

# Development and Validation of the Carer Well-Being and Support (CWS) Questionnaire

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*Report for the National Institute for Health  
Research Service Delivery and Organisation  
programme*

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prepared by

Alan Quirk<sup>1</sup>

Sarah C. Smith<sup>2</sup>

Sarah Hamilton<sup>3</sup>

Donna L. Lamping<sup>2</sup>

Paul Lelliott<sup>1</sup>

Daniel Stahl<sup>4</sup>

Vanessa Pinfold<sup>3</sup>

Manoharan Andiappan<sup>4</sup>

<sup>1</sup> Royal College of Psychiatrists

<sup>2</sup> London School of Hygiene & Tropical Medicine

<sup>3</sup> Rethink

<sup>4</sup> Institute of Psychiatry

Address for correspondence:

Alan Quirk, PhD  
Senior Research Fellow  
Royal College of Psychiatrists  
Standon House  
21 Mansell Street  
London, E1 8AA  
Email: [aquirk@cru.rcpsych.ac.uk](mailto:aquirk@cru.rcpsych.ac.uk)

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# 1 Background

## *1.1 Introduction*

The SDO commissioned a review of outcomes tools for carers of people with mental health problems and dementia (Harvey et al., 2005). The review recommended one instrument, the Carers' and Users' Expectations of Services – Carers' version (CUES-C), for further development and psychometric evaluation. SDO therefore invited the team that developed CUES-C to submit a proposal to undertake this work. The research was carried out between November 2006 and September 2008. The final report was modified in response to SDO reviewers' comments, and resubmitted in April 2009.

## *1.2 Aims of the Project*

The project had two main aims:

1. To review and revise CUES-C to produce a modified instrument that measures all important aspects of the experience of carers of people with severe mental health problems or dementia.
2. To evaluate the psychometric properties of the revised version of CUES-C in two-stage field testing.

The project team aimed to work closely with carers themselves, to ensure that the acceptability and relevance of the original CUES-C was retained in the revised instrument.

## *1.3 Project Team*

### **1.3.1 Research Partner Organisations**

The research team comprised four main partner organisations (below). The contributions of individual members of the team are described in later chapters. In addition, Daniel Stahl, Lecturer in Biostatistics at the Institute of Psychiatry, contributed to the design of the project, and he and his colleague Manoharan Andiappan carried out the psychometric re-analysis of the original CUES-C data in Phase 1 of the project (3.3). Rob Chaplin, Consultant Psychiatrist and Research Fellow at the Royal College of Psychiatrists' Research Unit, played a major role in recruiting carers through one of the NHS trusts involved in the final field trial (5.2.1).

### ***Royal College of Psychiatrists' Research and Training Unit***

The College Research and Training Unit (CRTU) at the Royal College of Psychiatrists works to improve mental health services, through research, development of guidance, quality improvement initiatives and education and training. The Royal College of Psychiatrists led the development of the original CUES-C instrument as well as the research described in this report.

Paul Lelliott, Director of the CRTU, Principal Investigator

Alan Quirk, Senior Research Fellow, Project Manager.

### ***Rethink***

Rethink is the leading national mental health membership charity. It has a strong carer focus, having been established by carers. Rethink was also one of the partners involved in developing the CUES-C, under its previous name of the National Schizophrenia Fellowship. Rethink provided access to carers for people with a mental health problem and were partners in revising and testing the questionnaire.

Vanessa Pinfold, Director of Research

Sarah Hamilton, Research Officer.

### ***Alzheimer's Society***

The Alzheimer's Society is the UK's leading care and research charity for people with dementia and those who care for them. The Alzheimer's Society provided access to carers for people with dementia and were partners in revising and testing the questionnaire.

Samantha Sharp, Senior Policy Officer

Louise Lakey, Senior Policy Officer.

### ***London School of Hygiene & Tropical Medicine, Health Services Research Unit***

The Health Services Research Unit at LSHTM carries out research to improve the quality, organisation and management of health services and systems. The unit has internationally recognised expertise in the development and validation of outcome measurement tools. The LSHTM led on all psychometric components of study design, analysis and reporting.

Donna Lamping, Professor of Psychology

Sarah Smith, Lecturer in Psychology.

### **1.3.2 Advisory Group**

The research team was supported by an advisory group which met in full on two occasions. The group provided comments on the project plan and on

versions of the revised questionnaire. Members also provided advice to the research team on specific aspects of the research.

The advisory group was made up of the following people: Maria Tuck (Alzheimer's Society, Performance and Information Systems Project Manager), Margaret Oates (CSIP Routine Outcomes Measures Project Manager), Angela Clayton-Turner (carer recruited through the Alzheimer's Society) and Janet McCrae (carer recruited through Rethink).

## ***1.4 About this Report***

The report describes how we developed and tested the *Carer Well-Being and Support Questionnaire (CWS)*.

Chapter 2 summarises the comments made about CUES-C in the SDO review and discusses the implications of the review for the work described in this report.

The next chapters describe in turn the three main phases of the research. Chapter 3 describes the 'deconstruction' of the original CUES-C and the development of a long version of a new questionnaire, the CWS-v1. Chapter 4 reports the preliminary field test of the long version CWS-v1, which used item reduction analyses to produce a scientifically-robust shorter version of the new questionnaire, the CWS-v2. Chapter 5 reports the final field test and psychometric evaluation of the short CWS-v2.

Chapter 6 discusses limitations, the uses of the new instrument, and recommendations for future research and development.

The different versions of the CWS, including all developmental versions and the final instrument, are provided as Appendices.

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## 2 Implications of SDO Review for the CUES-C Development Project

In 2005, the SDO commissioned a review of available outcome measures for carers of people with mental health problems or dementia (Harvey et al., 2005). This was to include consultation with a range of carers. The purpose of the review was to advise the SDO on: i. instruments that could be used to measure the outcomes of services from carers' perspectives; ii. the further work required to develop these instruments so that they are robust and iii. any outcomes considered important by carers for which measures have not been developed.

This chapter summarises the SDO reviewers' comments on the strengths and weaknesses of CUES-C, and discusses other findings which have implications for its redevelopment. By way of background, Appendix 1 describes the previous CUES-C work – how it was developed and its preliminary evaluation.

### 2.1 Comments on CUES-C

#### 2.1.1 Strengths

A key finding of the consultation exercise was that a broad range of outcomes should be assessed, because care-giving impacts on several aspects of carers' lives. CUES-C is one of only three instruments identified that attempted to assess a broad range of domains, all of which are considered important by carers themselves. Uniquely, it assesses carers' willingness to continue caring and whether the carer feels recognised for their role.

The reviewers also note that it has "rapidly attracted approval from clinicians and established a reputation for ease of use" (i.e. it scores highly on the psychometric criteria of acceptability to the intended population and feasibility or ease of use).

CUES-C was also noted as being one of only eight that involved carers in the generation of items, and the only measure that included carers on its advisory group.

#### 2.1.2 Areas for Development

Because the CUES-C had not undergone a full psychometric evaluation, the reviewers could not recommend it in its current form. However, its other advantages led the reviewers to recommend the urgent undertaking of studies to establish the psychometric properties of CUES-C.

The CUES-C was developed specifically for carers of people with mental illness. The SDO review was looking for measures which could be used both for carers of people with a mental illness and carers of people with dementia. This had considerable implications in the redevelopment of the CUES-C so that it could be used for both groups.

## ***2.2 Findings Relevant to CUES-C Redevelopment***

The SDO review also consulted with carers about what they wanted from an outcomes measure. These comments had important implications for the redevelopment of the CUES-C.

### **2.2.1 Carers find 'Outcome' to be a Problematic Concept**

The main difficulty the SDO reviewers faced in the consultation exercise was communicating the concept of an outcome to participants. The majority did not consider it very relevant to them, partly because carers found it extremely difficult to focus on themselves and their care-giving role, perhaps because they considered it selfish to do so. Despite these issues, the review team were able to obtain rich information about the aspects of care-giving that carers themselves considered important and, with probing, to determine the outcomes they considered to be important.

### **2.2.2 The Consultation Sample for the SDO Review was Probably Unrepresentative of the Intended Population**

Forty-four carers were consulted, almost all of whom were members of carer organisations. Carers who belong to carer organisations are likely to differ from carers who do not, but it is unclear how this difference affected the findings.

This finding has influenced how carers were recruited for the redevelopment of the CUES-C. As a result, it was agreed that recruitment for the second and final field trial of the new questionnaire (Chapter 5) should include carers identified through NHS trusts as well as through Rethink and Alzheimer's Society services and groups.

### **2.2.3 Instrument Constructs Identified by Carers as Important**

The SDO review asked carers to identify constructs which they felt were important to measure. These were:

- Depression and/or anxiety
- Mood or psychological well-being
- Physical and mental health
- How the carer feels about care-giving
- Satisfaction with caring

Burden

Effect of care-giving on the carer's family

Effect of care-giving on the carer's social life

Confidence in providing care

Professional support the carer receives

Coping

Satisfaction with life, and

Quality of life.

Most of the instruments reviewed were restricted to one domain. CUES-C was one of only three that incorporated several of them.

### **2.2.4 Three Broad Categories of Outcomes**

The numerous outcomes considered to be important by carers can be grouped into three broad categories:

(A) Outcomes related to the carer herself or himself, for example the carer's health or quality of life (i.e. 'wellbeing'). These are items that may be considered important by all individuals, regardless of whether or not they are carers.

(B) Outcomes related to the carer's experience of care-giving, such as the effect of care-giving on the carer's life or the knowledge of the care recipient's illness. This group of outcomes would be relevant only to carers, although not restricted to carers for people with MH problems of dementia.

(C) Outcomes related to the services that the carer received or services provided to the person cared for that impact on the carer. These included the accessibility or effectiveness of services. This group comprises outcomes that would likely be relevant to any individual receiving a service.

The categories had important implications for the breadth of coverage and the balance needed in the redeveloped CUES-C. Nonetheless, the CUES-C was well placed to address each of these categories.

### **2.2.5 It is Impractical to Assess all Constructs in a Single Evaluation?**

The reviewers conclude that it is impractical for researchers or service providers to attempt to assess all constructs in a single evaluation. Thus, they will need to make an informed choice as to which handful of domains is pertinent to the purpose of their evaluation. While the choice of which outcome(s) to assess should remain theirs, the outcome(s) selected must be considered important by carers (i.e. one that scores highly on the psychometric criterion 'acceptability').

Although the CUES-C had a broad coverage, this meant it was important to be explicit about what the redeveloped instrument did *and did not* cover.

### **2.2.6 Missing Outcomes that are Important to Carers**

There are two outcomes that are important to carers but for which no measure has yet been developed: i. morale and ii. receipt of emotional support.

## ***2.3 Conclusion***

The original CUES-C measure had been developed in partnership with carers and covered a broad range of issues of importance to carers. It also had attracted approval from clinicians. In light of the SDO review, the further development and revision of CUES-C provided a number of opportunities to build on the qualities of the original measure.

The key elements of the redevelopment include: i. maintaining the breadth and acceptability of the measure; ii. ensuring that the measure addresses issues relevant to carers of people with dementia as well as mental illness and iii. evaluating the psychometric properties of the measure to confirm its scientific rigor (reliability and validity).

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## 3 **Phase 1: The 'Deconstruction' of CUES-C**

This chapter describes how the original CUES-C questionnaire was deconstructed and the new version created. Known as 'CUES-C Version 2' in original protocol, the new questionnaire came to be re-titled the ***Carer Well-Being and Support Questionnaire (CWS)*** because the research team thought this better reflected its content. The deconstruction process was more involved and took longer than was anticipated at the outset of the study. We describe it step by step below.

### 3.1 *Objectives*

The purpose of this first phase of the study was to review and revise CUES-C so that the first field trial version became an instrument that measures all important aspects of the experience of carers of people with mental health problems or dementia.

### 3.2 *Overview of Phase 1*

The original questionnaire was 'deconstructed' over a period of four months; this culminated in the production of a new questionnaire (the CWS-v1). The research team: i. reanalysed existing CUES-C field trial data in order to evaluate the psychometric properties of the original questionnaire; ii. ran workshops to get feedback from carers on how to improve the questionnaire; iii. redrafted the questionnaire on the basis of the psychometric reanalyses and carer feedback; iv. consulted carers on the advisory group who checked the redrafted instrument and recommend improvements; v. incorporated improvements recommended by the psychometricians in the research team; vi. pilot tested the redrafted questionnaire with a small sample of carers and vii. finalised the new questionnaire, which was subsequently tested in a preliminary field test (see Chapter 4) .

### 3.3 *Psychometric Re-analyses of Existing CUES-C Data (Jan 2007)*

The initial stage of deconstruction was the re-analysis of the existing CUES-C data collected for the 1998/99 field trial (Chapter 2). Standard psychometric analyses were undertaken by Daniel Stahl and Manoharan Andiappan, under the supervision of Donna Lamping, in order to help identify: i. the construct or constructs measured by CUES-C and ii. the items on the questionnaire which performed well from a scientific point of view. Standard item analyses examined:

1. acceptability (e.g. identify items with a high number of missing responses or with large floor/ceiling effects, items which are highly correlated and thus redundant);
2. internal consistency (Cronbach's alpha of  $> 0.70$  and acceptable item/total correlations) and test-retest reliability ( $ICC > .80$ ), and
3. subscale structure (using factor analysis and item convergent and discriminant validity).

These analyses were carried out initially at the item level, and then at the subscale and total score levels. The main conclusions were:

- CUES-C does not meet the criterion for internal consistency reliability - that is, the 13 questionnaire items do not all measure the same construct;
- none of the 13 items are highly correlated, indicating that no items were redundant and
- the instrument needed rescaling, to either a 4- or 5-point scale.<sup>1</sup>

The key finding of the re-analysis was the separation of two distinct factors or constructs, which the research team identified as being 'Carer Support' and 'Carer Well-Being'. The first factor was constituted of the following domains: 'Help and advice'; 'Information about care workers'; 'Information about the illness'; 'Involvement in planning of treatment'; and 'Support for carers' (i.e. items 1-5 on original CUES-C). The second factor (items 6-13) was made up of 'Your own life'; 'Relationship with the person cared for'; 'Family and friends'; 'Money'; 'Own wellbeing'; 'Stigma'; 'Risk'; and 'Choice to care'.

### ***3.4 Workshops with Carers (Jan - Feb 2007)***

The parameters for the workshop discussions were to some degree pre-determined by the psychometric re-analyses of CUES-C data (3.3) and the SDO review of outcome measures (Chapter 2). This is reflected in the topic guides used by the workshop facilitators (Appendix 2). In January 2007 the research team agreed that the study should aim to develop an instrument that *measures two constructs* (i.e. well-being and support) rather than one that measures these plus additional constructs. Prompted by the SDO

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<sup>1</sup> Reliability can be improved by up to 0.1 by increasing the scale from 3 to 5 steps (Streiner & Norman, 2003). Furthermore, the responses of several CUES-C items were skewed towards one of the two extremes. Allowing more opportunities to express an underlying continuum, by increasing the number of steps from 3 to 5, would further increase reliability within those items.

Review, the workshops also explored whether and how issues of 'morale' and 'respite' might be addressed in the questionnaire.

### 3.4.1 Qualitative Methods

The three workshops were undertaken at weekly intervals in January - February 2007. They were facilitated either by Alan Quirk and Vanessa Pinfold (Workshops 1 & 3), both of whom are experienced in qualitative research, or Alan Quirk and Angela Clayton-Turner (Workshop 2).

*Workshop 1 (n=5):* carers for a person with psychosis (typically schizophrenia or bi-polar affective disorder)

*Workshop 2 (n=8):* carers for a person with dementia

*Workshop 3 (n=10):* carers for a person with a common mental health problem (typically depression or a phobia).

Participants were sent a copy of CUES-C in advance of the meeting so they could familiarise themselves with the instrument. The discussions were loosely structured around key topics (Appendix 2). The facilitators were free to word questions as they wished, and to follow up interesting topics with further supplementary questions. They encouraged a virtual dialogue between groups, by feeding back what carers in the other groups had said (e.g. "Carers in the last week's group said x,y,z. Do you agree?"). This made it possible to identify similarities and differences in the experiences and views of the different groups of carers. The facilitators aimed to elicit suggestions for improving the questionnaire, for example by:

- adding or removing items/questions;
- dividing single items into two or more items;
- changing the wording of the domain title, the normative statement or the question, and
- changing the number or wording of the response categories.

The initial psychometric re-analyses (inter-item correlations) identified items 4, 5, 7, 10, 12 and 13 on the original CUES-C instrument as being particularly problematic. These items were focussed on during the workshop discussions to see how they might be improved.

All workshops were audio-taped and fully transcribed, resulting in a qualitative database of 42,000 words. A simple coding scheme was constructed, based on issues covered by the topic guide; that is, 'general comments', 'problems' and how to improve 'specific CUES-C items' (questions 1-13). Workshop transcripts were indexed using the coding scheme. The analyst (Alan Quirk) retrieved and examined all comments relating to each CUES-C item, and to the questionnaire as a whole. Once this text was retrieved, it was further subcategorised into 'positive' and 'negative' comments, and comments that explicitly or implicitly indicated the need for a 'change' to the questionnaire or a specific question. This

straightforward approach to thematic qualitative analysis is described in numerous textbooks (for example, Seale (2004: 313-321)).

### 3.4.2 Carers' Experiences

The workshops proved to be a very rich source of data about carers' experiences, as these quotes illustrate:

"There comes a time in your life where you've got to say, well, I deserve a life, I deserve some time..." [Carer in Common Mental Health Problem (CMHP) Workshop]

"... you've got that constant worry and stress and anxiety..." [Psychosis Workshop]

"Sometimes I'm ashamed of what I do, frankly." [Dementia Workshop]

"I had to be with her 24 hours, with her. I couldn't even sleep at night." [Dementia Workshop]

"I spent three days trying to track down a person to get help, because I didn't know who to go to." [CMHP Workshop]

"I was always worried he would turn the gas on and forget to turn it off." [CMHP Workshop]

### 3.4.3 Carer Feedback on CUES-C 'Problem' Items

To illustrate further the type of feedback provided by carers, we summarise below the content of workshop discussions about three 'problem' items on CUES-C.

#### *CUES-C Question 10*

##### **'Your wellbeing'**

*Many carers experience a range of effects on their wellbeing. Common examples are depression, anxiety and stress, which can have effects such as sleeplessness and loss of physical fitness. On the other hand, people can feel a greater sense of fulfilment and purpose as a result of care-giving activities.*

##### ***How well are you feeling?***

*As good as I would like* ☐

*Not as good as I would like* ☐

*Much worse than I would like* ☐

***Summary of feedback from Workshop 1 (carers for a person with psychosis):*** Carers in this group suggested dividing this into three questions addressing carers' problems/needs concerning: (1) physical health, (2) mental health (anxiety, depression), (3) other (inability to sleep, stresses and strains).

**Summary of feedback from Workshop 2 (carers for a person with dementia):** Participants agreed with Workshop 1's suggestion for dividing up the question as it seemed to cover too much at present. They suggested having separate questions about your physical health and emotional wellbeing. Constantly feeling completely tired-out is a huge problem. Sleeplessness can be caused by your sleep being disturbed by the person you care for (e.g. by them wandering about in the middle of the night), or through worries and anxiety i.e. you can lose sleep for different reasons. The older participants in the group (including one who was 87) were very concerned about the consequences of their ailing physical health for themselves and the person cared for. Falls are a major worry - if you fall in your home, how do you call for help, given that the person you care for is unable to do this for you? And if it happens on the street, and you get knocked unconscious, how will people know about the person at home who depends on you? (Participants offered each other advice about this – for example, some carry a card in case of an accident, which states that there is someone at home who is dependent on them.)

### **CUES-C Question 13**

#### **'Choice to care'**

*Carers should have a choice about whether to continue as a 'carer'. If carers decide they want to stop, support should be available to help them make the break, and they should be able to find out about the alternatives that are available for the person they care for.*

***To what extent do you feel you have a choice about whether to continue as a carer?***

*As much as I would like* ☐

*Not as much as I would like* ☐

*Much less than I would like* ☐

**Workshop 1 feedback (psychosis):** This question needs lots of work. The decision to 'end' the caring role is simply not an option for the vast majority of carers. More relevant are the questions "What happens if I die first?", and "How will the person I care for be supported when I'm gone?" The question should not be about ending your caring role, but more about *changing* it so that it is not so draining. Carers need support that allows them make the choice to care not-quite-so-much without feeling guilty about it.

**Workshop 2 feedback (dementia):** One carer expressed wry amusement about this question – she and the other spouse carers in the group did not perceive themselves as having a choice because the only alternative was to put the person into an expensive care home. It is easier to care if you are a retired spouse, because you have time to do so; it is more of a problem for others (e.g. carers for a parent) who have to work to support the family. Caring for a parent in a family home affects everybody,

not just the main carer. A greater level of support can allow you to continue your caring role for longer, because your personal "breaking point" is not reached so soon (if it is reached at all). The idea of there being a choice to care made more sense to carers in the group who were not spouses.

### **CUES-C Question 7**

#### **"Relationship with the person you care for"**

*Carers want to be able to stay on good terms with the people they care for. The relationship between carers and the people they care for can often become strained.*

***To what extent is your relationship with the person you care for strained at the moment?***

*Not at all* ☐

*A little* ☐

*A lot* ☐

***Workshop 2 feedback (dementia):*** The strains of caring for someone with Alzheimer's can become intolerable. For example, you might have to cope with eight hours of non-stop screaming, liquids being thrown around at meal times and constant repetitive questioning ("What day is it?" ad infinitum). Participants spoke of how such things can make you cross – even though you are aware the person does not know what they are doing – and also about how they sometimes felt "ashamed" of their reaction (e.g. shouting back). It can reach "breaking point" where you finally realise you cannot carry on like this, and decide to put the person into a home. For some, incontinence represented their breaking point. Some participants asked how the hell you can be helped with such things, and questioned whether filling in a questionnaire would make any difference. However, the group offered each other valuable advice on such matters (e.g. using a children's beaker with lid to stop liquid being chucked about, or using particular types of incontinence pants) that was well taken. As well as strains in their relationship, carers expressed feelings of bereavement over the loss of the person they loved. With Alzheimer's, there is typically a change in the nature of the relationship as the illness progresses, for example from 'supporter' to 'carer', or perhaps to almost a 'parent-child' relationship. This can be very upsetting and extraordinarily difficult to deal with.

***Workshop 3 feedback (common mental health problems):*** Carers in this group spoke of how the strains in the relationship can change from day to day, even hour to hour, and so felt that a question about how strained the relationship is "at the moment" could be misleading. Some found the follow-up question, about whether you would like more help with this, confusing because they did not know what 'help' means in this context – for example, does it refer to physical help, respite, counselling etc? The strains

in the relationship can be immense. For example, how do you cope if the person you are caring for has an affair, but you are constrained from ending the relationship because of your caring responsibilities to that person? There is typically a lack of balance in carer/cared for relationship – for at least one carer in this group, there was “none of the kind of stuff” like your partner sometimes cooking for you. The person cared for can be very demanding. For example, a spouse carer told the group of how her husband does not like being left alone, so she has to stay by his side much of the time. Unfortunately, he also hates noise so demands she stays silent while she is with him.

### **3.4.4 Using Feedback from the Workshops**

The three workshops were an important beginning of the attempt to re-develop the CUES-C questionnaire to make it acceptable to the broad range of carers for people with dementia or a mental health problem. The workshops generated much useful feedback from a diverse group of carers. Participants indicated improvements such as adding new items/questions, dividing up existing items into two or more separate items, or modifying normative statements at the beginning of each item.

## ***3.5 Redrafting by the Research Team (Feb - Mar 2007)***

We used the workshop feedback to revisit the items of the original CUES-C, to break them down into more specific topics or to develop new domains where the participants had felt that something important had not been covered. On the basis of the feedback, we made the following changes:

- ‘Your well-being’ (CUES-C question 10) was divided into two separate domains – ‘Your physical health’ and ‘Your emotional wellbeing’;
- ‘Risk and safety’ (CUES-C question 12) was split into ‘Risk’ (to the carer) and ‘Safety of the person you care for’;
- ‘Support for carers’ (CUES-C question 5) was broken down into ‘Care worker support received by the person you care for’, ‘Care worker support received by you’, ‘Support from other people’ and ‘Respite’, and
- new domains were added, namely ‘Changing your caring role’ and ‘Communication with care workers’.

During re-drafting, ‘Care worker support’ was changed to combine support received by the carer and support received by the person they care for. The project team agreed that the two constructs ‘Well-Being’ and ‘Support’

would remain distinct in the revised version of the questionnaire and would be scored on two different scales.

Drawing on feedback from workshops participants, and on the advice of the team's measurement experts (Donna Lamping and Sarah Smith), the format of the questionnaire was changed by the research team from the distinctive style used for CUES-C (see 3.6). Carers had observed that the three-point scale could be "frustrating" and requested additional response categories. They also felt that the normative statements often implied unrealistic expectations (for example, see workshop feedback above about CUES-C Question 13: 'Choice to care'). The question stem for all items in the 'Well-Being' section was initially established as '*How worried are you about...*' with a 5-point scale ranging from 'A lot' to 'Not at all'. The 'Support' questions used the question stem '*How satisfied are you...*', with a 4-point scale ranging from 'Extremely satisfied' to 'Not at all satisfied'.

The research team also decided that a time frame of four weeks should be added to the 'Well-Being' questions but not to the 'Support' questions as carers may not have had contact with care staff within that period, in which case they would be unable to answer certain questions.

### 3.6 Formats of Questionnaires Compared

The format of the re-drafted questionnaire was thus very different to the original CUES-C. Below we compare one of the items on the original CUES-C (Question 2: 'Risk and Safety') with the questions that replaced it on the new questionnaire.

#### 3.6.1 Example: Questions about Risk and Safety

##### *CUES-C Question 2*

###### **'Risk and Safety'**

*Carers should not have to worry about their own safety or that of the person they care for.*

***To what extent do you feel worried about your own safety or that of the person you care for?***

*Not at all* ☐

*A little* ☐

*A lot* ☐

***Would you like more help in dealing with risk or safety issues?***

*Not at all* ☐

*A little* ☐

*A lot* ☐

***What particular areas would you like more support with?***

[space for free text response]

### ***Replacement questions on the re-drafted questionnaire<sup>2</sup>***

#### **“Your own safety”**

The next questions ask about aspects of **your own safety**. (Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how worried</b> were you about the person you care for...	A Lot	Quite a bit	Moder- ately	A little	Not at all
Accidentally doing something that puts you at risk (e.g. leaving the gas on)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being aggressive or threatening towards you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Saying cruel or hurtful things that upset you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

#### **“The safety of the person you care for”**

The next questions ask about aspects of **the safety of the person you care for**. (Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how worried</b> were you about the person you care for...	A Lot	Quite a bit	Moder- ately	A little	Not at all
Harming themselves accidentally	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Harming themselves deliberately	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Getting themselves into dangerous situations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Getting unwell/relapsing/deteriorating, such that it put their safety at risk	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### ***3.7 Consultation with Carers (Apr 2007)***

We sent copies of the completed draft of the revised questionnaire to the two carers on the advisory group (Angela Clayton-Turner and Janet McCrae) and an independent researcher working on carer-related research (Anne Arber). Feedback was generally very positive, indicating that the new instrument was likely to be acceptable to carers. Their comments at this

<sup>2</sup> This extract is from the questionnaire precisely as it was at this stage in the development process; that is, after it had been redrafted by the research team (3.5) but before it was sent to carers for comments (3.7). We made further changes to this part of the questionnaire before it was finalised, such as changing the question stem from ‘how worried were you...’ to ‘how concerned were you...’ (3.9).

stage led to a number of changes to the questionnaire, with questions added about:

- feeling irritable with the person cared for;
- getting into debt;
- being unable to afford bills or housing costs;
- worries that the person being cared for is unable to cope with difficult situations;
- sexual aggression towards the carer;
- the affordability and adequacy of respite care;
- whether the carer knows who should provide them with information and advice; and
- the carer's ability to find information for his/herself.

The carers consulted at this stage also recommended clearer or more acceptable language for a number of items. The need to make the questionnaire accessible for people who care for more than one person was also raised. In subsequent discussions, the research team agreed that this was best dealt with by acknowledging, in the instructions page, the possibility of this situation and asking carers to consider their situation as a whole when answering questions.

### ***3.8 Review by Measurement Experts (Apr 2007)***

Following review by the team's measurement experts, the following changes were made to the draft questionnaire:

- 'Ability and choice to care' and 'Your role as a carer' were merged into one domain but retained the questions already drafted; and
- three domains relating to information and advice for carers ('Availability of information', 'Information about services for the person you care for', and 'Information about mental illness and its effects' ) were merged into a single domain, namely 'Information and advice for carers'.

### ***3.9 Pilot Testing of the Re-Drafted Questionnaire (Apr 2007)***

The re-drafted questionnaire, consisting of 16 domains and a total of 74 questions, was sent to the 23 carers who took part in the workshops (3.4),

seven of whom responded. Participants were asked to complete the questionnaire and provide comments.

In addition, Alan Quirk and Sarah Hamilton attended a coffee morning run by an informal group of carers for people with dementia in order ask participants for their views on the questionnaire. This informal 'workshop' was organised by Angela Clayton-Turner and lasted approximately 90 minutes. The group included two carers who had attended the workshops and four others who had not been involved in the study up to this point.

The consensus from carers who had been involved in the workshops was that the new questionnaire was a big improvement on the original CUES-C, both in the broader range of topics covered and the ease of use.

Feedback from this pilot test led us to make the following changes:

- the question stem for all items in the 'Well-Being' section of the questionnaire was changed from 'how worried' to 'how *concerned*', which was felt to be less strong and thus more broadly acceptable; and
- a new question was added about having to keep the illness of the person cared for a secret because he/she did not want others to know about it (item 30 on the long version of the CWS).

### **3.10            *Finalisation of CWS-v1 (Apr 2007)***

A review of all workshop data and discussions within the research team led us to make a number of final changes to the wording and layout of the questionnaire:

- a question was added around concerns about not getting needed support from family and friends (CWS-v1 question A13);
- a question was added to ask how satisfied carers are with their relationships with key staff who support the person they care for (CWS-v1 question 19);
- one question, which asked about being able to take a break without feeling guilty, was removed because it was double-barrelled;
- the communication and support from care staff domains were merged to form a single domain, namely 'Support from medical

and/or care staff' (individual questions in those domains were unchanged); and

- 'not applicable' response categories were added to the domains 'Support from other carers' and 'Taking a break ('respite')', because otherwise carers who did not receive support from other carers or had not tried to access respite care would be unable to respond (see example below).

**Example: addition of 'not applicable' response category to question about respite**

In general, how satisfied are you...	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
29. with how easy it is for you to get respite care locally?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Not applicable; I have not tried to get respite care				

The final long version of the questionnaire, entitled the *Carer Well-Being and Support Questionnaire (version 1)* or 'CWS-v1', is presented in Appendix 6.

### 3.11 Questionnaire 'Map': from CUES-C to CWS-v1

The table below compares the domains covered by original CUES-C questionnaire and those in the new CWS-v1. The central column summarises feedback from the workshops (3.3). The table tells part of the story of how the domains covered by the revised questionnaire emerged. Appendix 7 holds an item tracking device, which is essentially a fuller audit trail for individual concepts and questionnaire items.

**Table 1. Questionnaire 'map': from CUES-C to CWS-v1**

DOMAINS COVERED BY CUES-C	WORKSHOP SUGGESTIONS	DOMAINS COVERED BY CWS-v1
Domain 1: How to get help and advice	Do not change	Domain 11: Information and advice for carers
Domain 2: Information about care workers	Do not change	
Domain 3: Information about mental illness and its effects	Do not change	

Domain 4: Involvement in planning of treatment and care	Involvement in treatment and care planning	Domain 12: Your involvement in treatment and care planning
Domain 5: Support for carers	Communication with care workers Availability of support from care workers Adequacy of care worker support Availability of support from other people Adequacy of support from other people Respite	Domain 13: Support from medical and/or care staff
		Domain 14: Support from other carers
		Domain 15: Taking a break ('respite')
Domain 6: Your own life	How you spend your time	Domain 1: Your day-to-day life
Domain 7: Relationship with the person you care for	Do not change	Domain 2: Your relationship with the person you care for
Domain 8: Family and friends	Do not change	Domain 3: Your relationships with family & friends
Domain 9: Money	Do not change	Domain 4: Your financial situation
Domain 10: Your wellbeing	Your physical health Your emotional health Your morale	Domain 5: Your physical health
		Domain 6: Your emotional well-being
Domain 11: Stigma & discrimination	Do not change	Domain 7: Stigma & discrimination
Domain 12: Risk and safety	Risk Safety of the person you care for	Domain 8: Your own safety
		Domain 9: The safety of the person you care for

Domain 13: Choice to care	Your caring role Choice to care	Domain 10: Your role as a carer
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### **3.12            *Revisions to Background Information Section***

The Background Information section in CWS-v1 was largely unchanged from equivalent section in CUES-C. Aside from a few tweaks to the format and sequencing of questions, the main difference was the addition of the following questions:

- How many people do you currently care for?
- Are you the main carer?
- What is the illness/condition of the person you care for?

### **3.13            *Conclusion***

The results of the psychometric analyses of data from the previous study to develop the CUES-C, together with the recommendations of the SDO review and the feedback from the workshops with carers, informed the revision of the CUES-C. The challenge was to develop a scientifically robust tool that adequately captures carers' experiences.

The new version of the questionnaire - the CWS-v1 - covers similar domains to those in the original CUES-C, but ended up looking very different. The decision to modify the questionnaire so radically was made by the research team in January 2007, and was partly informed by the results of the psychometric analyses of CUES-C data from the previous development study. We were concerned to retain those aspects of the questionnaire that led to it being recommended for re-development in the SDO review (Harvey et al., 2005), so the deconstruction process was managed very carefully.<sup>3</sup>

In the original protocol, one month (Month 4) was allotted for this; however, this was extended to four months to ensure a psychometrically robust questionnaire acceptable to carers.

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<sup>3</sup> Our main concern at this stage of the development process was to ensure that the new instrument addressed the broad range of issues covered by the CUES-C. Later, we addressed something important that had been lost in the transformation; namely the opportunity the CUES-C gave clinicians to assess carers' needs for support, derived the follow-up question after each item (e.g. "What particular areas would you like more support with?"). To maximize the clinical utility of the CWS, we added a separate needs assessment component – "Part C: Your Needs" - to the final version (Appendix 7).

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## 4 **Phase 2: Preliminary Field Test and Revision of CWS-v1**

The CWS-v1 was subjected to a preliminary field test, to reduce the number of items and undertake a preliminary evaluation of the psychometric properties of the shorter, item-reduced version of the questionnaire. We posted CWS-v1 questionnaires to carers for people with a mental health problem (MHP) or dementia, selected randomly from service caseloads at Rethink and the Alzheimer's Society. Standard item analyses were performed to produce an item-reduced revised instrument (the CWS-v2). Qualitative feedback from respondents was analysed to gauge the acceptability of the questionnaire and identify how the instructions and Background Information section could be improved.

### ***4.1 Objectives***

The purpose of this phase of the study was to evaluate the long (74-item) CWS-v1 and produce a scientifically-robust shorter version of the questionnaire.

### ***4.2 Sampling, Recruitment and Questionnaire Administration (May – Aug 2007)***

The initial long version of the Carer Well-Being and Support Questionnaire (CWSv1; Appendix 3), used in the preliminary field test, includes two scales. The first was 43-item *Well-Being scale* consisting of ten domains:

- Your day to day life
- Your relationship with the person you care for
- Your relationships with family and friends
- Your financial situation
- Your physical health
- Your emotional well-being
- Stigma and discrimination
- Your own safety
- Safety of the person you care for
- Your role as a carer.

The second was a 31-item *Support scale* consisting of five domains:

- Information and advice for carers
- Your involvement in treatment and care planning
- Support from medical and/or care staff
- Support from other carers
- Taking a break ('respite').

A total of 488 questionnaires were distributed via five AS branches and 10 Rethink services or carer support groups across England. Between 10 and 60 questionnaires were sent out through each service/group, depending on their size of caseload. Alan Quirk, working closely with Samantha Sharp (AS Senior Policy Officer), took the lead on AS recruitment. Sarah Hamilton, supported by Vanessa Pinfold and other staff at Rethink HQ, led the recruitment through Rethink. We selected services according to these criteria:

- willingness of the managers/staff to take part in the trial
- numbers of carers currently using the service (the more the better, with a caseload of 60+ being essential)
- diversity
- ease of random sampling – including the method of keeping records in the service.

The research team prepared the questionnaires for distribution and took them to each service. Each questionnaire carried a handwritten unique identifier which included a code for the service through which it was sent. Using a list of randomly generated numbers, a member of the research team (Alan Quirk or Sarah Hamilton) visited the service and identified carers from a numbered mailing list or database. Conferring with service staff, any carer identified who did not meet the criteria for participation was replaced by the next number on the list until sufficient numbers were sent out. Criteria for participation were: i. currently caring and ii. has been in touch with the service in the past 6 months (indicating that they are a 'current' user of the service).

We posted questionnaires directly from the service using names and addresses held in the service. A note was made of the unique identifier on the questionnaire and the corresponding participant. This record was kept in the service or held by the carer support group co-ordinator. This ensured that the research team did not take away any personal information which could be used to identify potential participants; it stayed within the service.

Respondents completed the 74-item CWS, then answered demographic and background questions. The questionnaires were returned anonymously in postage-paid envelopes to Alan Quirk at the RCPsych or Sarah Hamilton at Rethink. The research team kept a record of the unique identifiers on the questionnaires returned. After approximately two weeks, we identified those unique identifiers that had yet to be returned and visited each service

a second time to post reminder letters to non-respondents. All respondents were entered into a prize draw.

Following advice from the National Research Ethics Service, we did not seek NHS research ethics approval for this part of the study. Our reasoning was that participants were recruited through our research partners Rethink and the Alzheimer's Society in the capacity of clients of their own services, not in the capacity of patients or carers through the NHS. However, given the potential vulnerability of carers, Rethink and the Royal College of Psychiatrists carefully reviewed the protocol using internal research procedures. For the latter, this involved checking that the procedures adhered to guidance on ethics in the DH research governance framework (Department of Health, 2005, pp.7-9).

The procedures in the preliminary field test complied with data protection legislation in that participants did not record their name on the questionnaire, no identifiable information was recorded by the research team, and respondents could only be identified by cross-checking the list of IDs on returned questionnaires (held in locked filing cabinets at the Royal College of Psychiatrists and Rethink) against the lists of individuals who had been sent a questionnaire (stored at the participating services). Such cross-checking occurred: i. when the research team re-visited services to identify who to send reminder letters to (those who had not responded after two weeks), and ii. to identify the winner and runners-up in the prize draw.

### ***4.3 Psychometric Evaluation: Item Reduction Analyses of Long (74-item) CWSv1 (Sep – Nov 2007)***

#### **4.3.1 Objectives**

The objectives of the item-reduction stage of the psychometric evaluation of the long (74-item) CWSv1 were to:

1. confirm the feasibility and acceptability of the questionnaire;
2. produce a scientifically robust shorter version of the questionnaire by selecting items that perform best against psychometric criteria;
3. identify subscales and test scaling assumptions; and
4. carry out a preliminary evaluation of the psychometric properties of the shorter item-reduced CWS-v2.

#### **4.3.2 Psychometric Methods**

##### ***Item reduction analyses***

The purpose of the item reduction analyses, which were undertaken by Sarah Smith and Donna Lamping, was to produce a psychometrically robust

short version of the CWS. To do so, we carried out several iterative rounds of standard psychometric item reduction analyses of the long (74-item) CWSv1 to identify and retain items with strong psychometric properties. These analyses were guided by a well-defined a priori item reduction strategy developed in our extensive and pioneering previous work in this area (Lamping *et al.*, 2002, 2003). On the basis of standard psychometric tests and criteria (Streiner & Norman, 2003; Scientific Advisory Committee, 2002; Lamping *et al.*, 2002, 2003), items with poor measurement properties were eliminated (and those with acceptable psychometric properties retained) to produce a shorter, item-reduced version of the CWS questionnaire. These analyses also evaluated the hypothesised subscales of the questionnaire.

Table 2 summarises the psychometric tests and criteria we used. Item reduction analyses were carried out at both the item and scale level. First, we performed item-level analyses separately for the CWSv1 Well-Being (43 items) and Support (31 items) scales. For each item, we evaluated the psychometric performance of that item against pre-specified criteria to evaluate whether the item should be retained or eliminated (see Table 2). Then we performed tests of scaling assumptions to confirm the appropriateness of combining a priori groups of items into scales, and to assess the potential for further item reduction, by investigating whether items: i) are correctly grouped into scales; ii) in the same scale measure the same construct; and iii) can be summed to produce a summary score.

**Table 2. Psychometric Tests and Criteria**

	<i>Psychometric test/analysis</i>	<i>Criterion for retention</i>
<b>Item level analyses</b>	Missing data	≤5%
	Maximum endorsement frequencies (floor/ceiling effects)	≤80%
	Item redundancy (inter-item correlations)	≤0.75
	Internal consistency (item-total correlations)	≥0.40
<b>Scale level analyses</b>		
<i>Acceptability</i>	Missing data	≤5%
	Floor/ceiling effects	≤10%
	Skew	-1.00 to 1.00
<i>Reliability</i>	Internal consistency (Cronbach's alpha)	≥0.70
	Internal consistency (item-total correlations)	≥0.40
	Test-retest reliability (intra-class correlations)	≥0.70
<i>Validity (within scale analyses)</i>	Factor analysis (using principal axis factoring, varimax rotation, with criteria for elimination applied to 2-factor model). In the preliminary field test, 10, 9, 8, 7, 6, 5, 4, 3 and 2 factors were requested in successive models.	≥0.40 on all factors and/or loading ≥ 0.40 on more than one factor with a difference between loadings <0.20
	Item convergent and discriminant validity analyses (item own-scale vs. item other-scale correlations)	"definite" or "probable" scaling success <sup>Ware et al., 1997</sup>

These analyses were conducted in three stages, including an examination of:

*Stage 1:*

- missing data
- maximum endorsement frequencies
- item redundancy

*Stage 2:*

- internal consistency

*Stage 3:*

- factor analysis
- item convergent/discriminant validity.

***Preliminary psychometric analyses of short (item-reduced) questionnaire***

We undertook a preliminary psychometric evaluation of this short questionnaire (item reduced CWSv1) by carrying out standard psychometric tests (see Table 5) on total and subscale scores, including:

- acceptability
- reliability (internal consistency)
- validity (factor analysis, item convergent/discriminant validity).

### **4.3.3 Results**

***Response rates and respondent characteristics***

Completed CWS-v1 questionnaires were returned by 210 carers of people with a mental health problem (MHP) or dementia (43% response rate).

Respondent characteristics are shown in Table 3. The mean age of respondents was 63 (SD: 13.4) and the majority were white (93%) and female (72%).

The large majority of respondents cared for a partner/spouse (n=94), parent (74) or son/daughter (28).

**Table 3. Respondent Characteristics**

<b>Variable</b>		<b>Preliminary field test (N=210)</b>
Age of carer	Mean (SD) Range (n)	63.3 (13.4) 21-100 (194)
Gender of carer	Male (%) Female (%)	56 (28) 145 (72)
Ethnicity of carer	White (%) Mixed (%) Asian or Asian British (%) Black or Black British (%) Chinese or other ethnic group (%)	188 (93.1) 4 (2) 6 (3) 4 (2) 0
Relationship with the person cared for <sup>1</sup>	Son/daughter Partner/spouse Brother/sister Parent Friend Other	28 94 5 74 3 7

***Item reduction analyses***

*Initial item reduction analyses* resulted in a 48-item version of CWSv1 (Table 4). Following discussion with the research team, we made the following minor modifications:

- item redundancy - (inter-item correlations) in determining which item in a pair of redundant items to eliminate, we retained A1 instead of A2, and A29 instead of A31
- item wording – we changed the wording of A34 from “harming themselves accidentally?” to “harming themselves?”

We then re-ran the item reduction analyses on this revised set of 48 items. Table 5 summarises the results of the *final item reduction analyses*, which resulted in a 49-item CWSv1.

Full details of the three stages of the final item reduction analyses which led to item elimination are shown in Tables 6 – 10, shown below.

In stage 1 of the analyses (conducted on the initial 74-item CWSv1), we eliminated 5 items from the Well-Being scale and 13 items from the Support scale to produce a *56-item reduced CWSv1*.

- Analyses of missing data and endorsement frequencies (Table 6) resulted in the elimination of 0 items from the Well-Being scale and 6 items from the Support scale (B25, B26, B28, B29, B30, B31).
- Analyses of item redundancy (Table 7) resulted in the elimination of 5 items in the Well-Being scale (A2, A20, A31,

A40, A43) and 7 items in the Support scale (B8, B17, B18, B15, B20, B23, B27).

In stage 2 of the analyses (conducted on the 56-item reduced CWSv1), we eliminated 5 more items from the Well-Being scale and 1 item from the Support scale to produce a *50-item reduced CWSv1*.

- Analyses of item-total correlations (Table 8) resulted in the elimination of 5 items in the Well-Being scale (A18, A29, A30, A35, A37) and 1 item in the Support scale (B5).

In stage 3 of the analyses (conducted on the 50-item reduced CWSv1), we eliminated 1 more item from the Well-Being scale to produce a *49-item reduced CWSv1*.

- Factor analysis (Table 9) resulted in the elimination of 1 item in the Well-Being scale (A17).
- Analyses of item convergent and discriminant validity (Table 10) confirmed that all items in the Well-Being and Support scales were classified as scaling successes, so no further items were eliminated.

Tests of scaling assumptions (conducted on the 49-item reduced CWSv1) provided support for separate Well-Being and Support scales and scores.

- Factor analysis (Table 11) clearly indicated a 2-factor model, which corresponded to the Well-Being and Support scales and accounted for 44.16% of the variance.
- Analyses of convergent and discriminant validity (Table 12) confirmed that items were correctly grouped into the two Well-Being and Support scales.

### ***Preliminary psychometric analyses of short (item-reduced) questionnaire***

The item reduction analyses described above resulted in a 49-item short CWSv1, comprising a 32-item Well-Being scale and 17-item Support scale (Appendix 6). Preliminary psychometric analyses of the short (item-reduced questionnaire) indicated a higher than expected level of missing data for both the Well-Being and Support scales (Table 13), but confirmed all other aspects of acceptability (floor/ceiling effects and skew of scale scores) and internal consistency reliability (Table 14) of both the Well-Being and Support scales.

**Table 4. Preliminary Field Test (Initial 74-item CWSv1): Item Reduction Criteria and Eliminations - Initial Item Reduction**

<b>CWS Well-Being (A1-A43)</b>	Initial alpha (43 items)	0.96 (n=179)
	<b>Criterion for elimination</b>	<b>Items eliminated</b>
Stage 1	Missing data >5%	None
	MEF >80%	None
	Inter-item correlations >0.75 <sup>1</sup>	A1/A2, A20/A21, A29/A31, A40/A41, A42/A43
	<b>5 items removed (38 remain)</b>	
Stage 2	Item-total correlations <0.40	A18, A26, A30., A31, A35, A37
	<b>6 items removed (32 remaining)</b>	
Stage 3	Factor analysis (loading <0.40 and/or cross loading)	A17
	Item convergent/discriminant validity (definite or probable scaling failure)	None
	<b>1 item removed (31 remaining)</b>	
	Final alpha (31 items)	0.95 (n=182)
<b>CWS Support (B1-B31)</b>	Initial alpha (31items)	0.97 (n=28)
	<b>Criterion for elimination</b>	<b>Items eliminated</b>
Stage 1	Missing data >5%	B25, B26, B28, B29, B30, B31
	MEF >80%	None
	Inter-item correlations >0.75 <sup>1,2</sup>	B7/B8, B14/B17, B14/B18, B15/B16, B17 <sup>†</sup> /B18, B19/B20, B22/B23, B22/B27, B24/B26, B26/B27, B30/B29, B31/B30 7 items eliminated: B8, B15, B17, B18, B20, B23, B27
	<b>13 items removed (18 remain)</b>	
Stage 2	Item-total correlations <0.40	B5
	<b>1 item removed (17 remaining)</b>	
Stage 3	Factor analysis (loading <0.40 and/or cross loading)	None
	Item convergent/discriminant validity (definite or probable scaling failure)	None
	Final alpha (17 items)	0.95 (n=175)

<sup>1</sup> For pairs of items, item eliminated is shown as A~~x~~. <sup>2</sup> Items highlighted have already failed missing criterion.

**Table 5. Preliminary Field Test (Initial 74-item CWSv1): Item Reduction Criteria and Eliminations - Final Item Reduction**

<b>CWS Well-Being (A1-A43)</b>	Initial alpha (43 items)	0.96 (n=179)
	<b>Criterion for elimination</b>	<b>Items eliminated</b>
Stage 1	Missing data >5%	None
	MEF >80%	None
	Inter-item correlations >0.75 <sup>1</sup>	A1/A2, A20/A21, A29/A31, A40/A41, A42/A43
	<b>5 items removed (38 remain)</b>	
Stage 2	Item-total correlations <0.40	A18, A29, A30, A35, A37
	<b>5 items removed (33 remaining)</b>	
Stage 3	Factor analysis (loading <0.40 and/or cross loading)	A17
	Item convergent/discriminant validity (definite or probable scaling failure)	None (item A15 possible query)
	<b>1 item removed (32 remaining)</b>	
	Final alpha (32 items)	0.95 (n=182)
<b>CWS Support (B1-B31)</b>	Initial alpha (31 items)	0.97 (n=28)
	<b>Criterion for elimination</b>	<b>Items eliminated</b>
Stage 1	Missing data >5%	B25, B26, B28, B29, B30, B31
	MEF >80%	None
	Inter-item correlations >0.75 <sup>1,2</sup>	B7/B8, B14/B17, B14/B18, B15/B16, B17/B18, B19/B20, B22/B23, B22/B27, B24/B26, B26/B27, B30/B29, B31/B30 7 items eliminated: B8, B15, B17, B18, B20, B23, B27
	<b>13 items removed (18 remaining)</b>	
Stage 2	Item-total correlations <0.40	B5
	<b>1 item removed (17 remaining)</b>	
Stage 3	Factor analysis (loading <0.40 and/or cross loading)	None
	Item convergent/discriminant validity (definite or probable scaling failure)	None
	Final alpha (17 items)	0.95 (n=175)

<sup>1</sup> For pairs of items, item eliminated is shown as A~~x~~. <sup>2</sup> Items highlighted have already failed missing criterion.

**Table 6. Preliminary Field Test (Initial 74-item CWSv1): Missing Data, Endorsement Frequencies**

<b>CWS Well-Being</b>	<b>Items failing criterion</b>
Missing data $\leq 5\%$	None
Maximum endorsement frequencies $\leq 80\%$	None
<b>CWS Support</b>	
Missing data $\leq 5\%$	B25 (5.2%), B26 (5.2%), B28 (51.4%), B29 (59.5%), B30 (59.5%), B31 (62.4%)
Maximum endorsement frequencies $\leq 80\%$	None

**Table 7. Preliminary Field Test (Initial 74-item CWSv1): Inter-Item Correlations**

<b>Item<sup>1</sup></b>	<b>Inter-Item Correlation</b>
<b>CWS Well-Being</b>	
A1/A2	0.82
A20/A21	0.78
A29/A31	0.83
A40/A41	0.80
A42/A43	0.76
<b>CWS Support</b>	
B7/B8	0.77
B14/B17	0.76
B14/B18	0.75 (0.7504)
B15/B16	0.76
B17/B18	0.92
B19/B20	0.79
B22/B23	0.77
B22/B27	0.77
B24/B26	0.77
B26/B27	0.79
B29/B30	0.86
B30/B31	0.76

<sup>1</sup> For pairs of items, item eliminated is highlighted.

<sup>2</sup> Items shown as A× have already failed the missing criterion.

**Table 8. Preliminary Field Test (Stage 2, 56-item reduced CWSv1): Item-Total Correlations**

<b>CWS Well-Being<sup>1</sup></b>	<b>Corrected item-total correlation</b>	<b>Alpha if item deleted</b>
A1	0.59	0.95
A3	0.64	0.95
A4	0.66	0.95
A5	0.60	0.95
A6	0.59	0.95
A7	0.53	0.95
A8	0.64	0.95
A9	0.75	0.95
A10	0.69	0.95
A11	0.64	0.95
A12	0.74	0.95
A13	0.60	0.95
A14	0.53	0.95
A15	0.49	0.95
A16	0.52	0.95
A17	0.44	0.95
A18	0.37	0.95
A19	0.63	0.95
A21	0.67	0.95
A22	0.74	0.95
A23	0.69	0.95
A24	0.70	0.95
A25	0.60	0.95
A26	0.403	0.95
A27	0.73	0.95
A28	0.53	0.95
A29	0.35	0.95
A30	0.36	0.95
A32	0.51	0.95
A33	0.55	0.95
A34	0.47	0.95
A35	0.34	0.95
A36	0.48	0.95
A37	0.398	0.95
A38	0.54	0.95
A39	0.59	0.95
A41	0.69	0.95
A42	0.71	0.95
<b>CWS Support<sup>1</sup></b>		
B1	0.60	0.95
B2	0.58	0.95
B3	0.67	0.95
B4	0.63	0.95
B5	0.34	0.95
B6	0.73	0.94
B7	0.75	0.94
B9	0.69	0.95
B10	0.72	0.94
B11	0.66	0.95
B12	0.66	0.95
B13	0.79	0.94
B14	0.78	0.94
B16	0.74	0.94
B19	0.74	0.94
B21	0.74	0.94
B22	0.80	0.94
B24	0.76	0.94

<sup>1</sup> Eliminated items are highlighted

**Table 9. Preliminary Field Test (Stage 3, 50-item reduced CWSv1): Factor Loadings**

	<b>Factor 1</b>	<b>Factor 2</b>
<b>CWS Well-Being</b>		
A1	.662	.029
A3	.654	.029
A4	.635	-.124
A5	.606	.000
A6	.585	-.046
A7	.518	-.053
A8	.659	-.016
A9	.765	-.128
A10	.636	-.234
A11	.597	-.214
A12	.720	-.139
A13	.590	-.084
A14	.417	-.256
A15	.424	-.300
A16	.451	-.294
A17	.322	-.215
A19	.611	-.110
A21	.700	-.075
A22	.756	-.133
A23	.692	-.122
A24	.696	-.162
A25	.585	-.055
A26	.445	.106
A27	.743	.002
A28	.449	-.233
A32	.532	-.040
A33	.538	-.094
A34	.468	-.091
A36	.439	-.108
A38	.454	-.244
A39	.597	-.096
A41	.741	-.120
A42	.734	-.129
<b>CWS Support</b>		
B1	.045	.603
B2	.030	.629
B3	-.032	.695
B4	-.037	.635
B6	-.138	.726
B7	-.170	.737
B9	-.210	.690
B10	-.133	.721
B11	.059	.706
B12	-.056	.687
B13	-.176	.781
B14	-.147	.777
B16	-.184	.756
B19	-.136	.752
B21	-.178	.737
B22	-.241	.802
B24	-.197	.776

<sup>1</sup> Eliminated items are highlighted.

**Table 10. Preliminary Field Test (Stage 3, 50-item reduced CWSv1): Item Own- vs. Item Other-Scale Correlations**

<b>N = 161</b>			<b>2(1/√n)</b>	
	<b>CWS Well-Being<sup>1</sup></b>	<b>CWS Support<sup>1</sup></b>	<b>2 SE</b>	<b>Scaling status</b>
A1	0.611	-0.087	0.158	Scaling success
A3	0.644	-0.082	0.158	Scaling success
A4	0.664	-0.207	0.158	Scaling success
A5	0.599	-0.076	0.158	Scaling success
A6	0.589	-0.150	0.158	Scaling success
A7	0.532	-0.121	0.158	Scaling success
A8	0.648	-0.128	0.158	Scaling success
A9	0.767	-0.235	0.158	Scaling success
A10	0.676	-0.281	0.158	Scaling success
A11	0.642	-0.269	0.158	Scaling success
A12	0.739	-0.235	0.158	Scaling success
A13	0.591	-0.160	0.158	Scaling success
A14	0.509	-0.262	0.158	Scaling success
A15	0.464	-0.313	0.158	Probable scaling success
A16	0.512	-0.304	0.158	Scaling success
A17	0.410	-0.198	0.158	Scaling success
A19	0.627	-0.170	0.158	Scaling success
A21	0.680	-0.153	0.158	Scaling success
A22	0.747	-0.230	0.158	Scaling success
A23	0.693	-0.211	0.158	Scaling success
A24	0.712	-0.243	0.158	Scaling success
A25	0.613	-0.132	0.158	Scaling success
A26	0.436	0.019	0.158	Scaling success
A27	0.734	-0.083	0.158	Scaling success
A28	0.503	-0.263	0.158	Scaling success
A32	0.519	-0.091	0.158	Scaling success
A33	0.552	-0.153	0.158	Scaling success
A34	0.479	-0.128	0.158	Scaling success
A36	0.464	-0.141	0.158	Scaling success
A38	0.506	-0.292	0.158	Scaling success
A39	0.579	-0.165	0.158	Scaling success
A41	0.691	-0.221	0.158	Scaling success
A42	0.720	-0.208	0.158	Scaling success
B1	-0.045	0.584	0.158	Scaling success
B2	-0.028	0.580	0.158	Scaling success
B3	-0.167	0.664	0.158	Scaling success
B4	-0.169	0.612	0.158	Scaling success
B6	-0.194	0.733	0.158	Scaling success
B7	-0.205	0.756	0.158	Scaling success
B9	-0.278	0.706	0.158	Scaling success
B10	-0.191	0.732	0.158	Scaling success
B11	-0.036	0.671	0.158	Scaling success
B12	-0.127	0.674	0.158	Scaling success
B13	-0.232	0.792	0.158	Scaling success
B14	-0.232	0.782	0.158	Scaling success
B16	-0.285	0.745	0.158	Scaling success
B19	-0.174	0.753	0.158	Scaling success
B21	-0.256	0.745	0.158	Scaling success
B22	-0.296	0.811	0.158	Scaling success

B24	-0.239	0.770	0.158	Scaling success
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<sup>1</sup> Item own-scale correlations are highlighted.

**Table 11. Preliminary Field Test (49-item reduced CWSv1): Factor Loadings**

	<b>Factor 1<sup>1</sup></b>	<b>Factor 2<sup>1</sup></b>
<b>CWS Well-Being</b>		
A1	.663	.028
A3	.653	.029
A4	.636	-.126
A5	.609	-.002
A6	.587	-.048
A7	.520	-.055
A8	.661	-.018
A9	.768	-.131
A10	.633	-.234
A11	.594	-.214
A12	.720	-.140
A13	.587	-.083
A14	.403	-.249
A15	.419	-.298
A16	.443	-.290
A19	.608	-.109
A21	.698	-.075
A22	.758	-.135
A23	.693	-.124
A24	.697	-.164
A25	.585	-.056
A26	.447	.105
A27	.743	.001
A28	.447	-.233
A32	.533	-.041
A33	.540	-.096
A34	.471	-.094
A36	.441	-.110
A38	.454	-.245
A39	.598	-.098
A41	.741	-.122
A42	.734	-.130
<b>CWS Support</b>		
B1	.043	.604
B2	.029	.630
B3	-.030	.695
B4	-.038	.636
B6	-.137	.727
B7	-.170	.738
B9	-.209	.690
B10	-.132	.721
B11	.059	.707
B12	-.055	.687
B13	-.176	.782
B14	-.146	.777
B16	-.183	.756
B19	-.135	.753
B21	-.177	.737
B22	-.241	.803
B24	-.196	.776

<sup>1</sup> Factor loadings  $\geq 0.40$  are highlighted.

**Table 12. Preliminary Field Test (49-item reduced CWSv1): Item Own-Scale vs. Item Other-Scale Correlations**

<b>N = 161</b>			<b>2(1/√n)</b>	
	<b>CWS Well-Being<sup>1</sup></b>	<b>CWS Support<sup>1</sup></b>	<b>2 SE</b>	<b>Scaling status</b>
A1	.615	-.087	0.158	Scaling success
A3	.645	-.082	0.158	Scaling success
A4	.667	-.207	0.158	Scaling success
A5	.604	-.076	0.158	Scaling success
A6	.592	-.150	0.158	Scaling success
A7	.536	-.121	0.158	Scaling success
A8	.654	-.128	0.158	Scaling success
A9	.774	-.235	0.158	Scaling success
A10	.671	-.281	0.158	Scaling success
A11	.637	-.269	0.158	Scaling success
A12	.740	-.235	0.158	Scaling success
A13	.587	-.160	0.158	Scaling success
A14	.480	-.262	0.158	Scaling success
A15	.454	-.313	0.158	Probable scaling success
A16	.495	-.304	0.158	Scaling success
A19	.623	-.170	0.158	Scaling success
A21	.680	-.153	0.158	Scaling success
A22	.754	-.230	0.158	Scaling success
A23	.695	-.211	0.158	Scaling success
A24	.714	-.243	0.158	Scaling success
A25	.614	-.132	0.158	Scaling success
A26	.441	.019	0.158	Scaling success
A27	.735	-.083	0.158	Scaling success
A28	.496	-.263	0.158	Scaling success
A32	.523	-.091	0.158	Scaling success
A33	.555	-.153	0.158	Scaling success
A34	.488	-.128	0.158	Scaling success
A36	.471	-.141	0.158	Scaling success
A38	.508	-.292	0.158	Scaling success
A39	.585	-.165	0.158	Scaling success
A41	.694	-.221	0.158	Scaling success
A42	.719	-.208	0.158	Scaling success
B1	-.045	.584	0.158	Scaling success
B2	-.028	.580	0.158	Scaling success
B3	-.169	.664	0.158	Scaling success
B4	-.169	.612	0.158	Scaling success
B6	-.194	.733	0.158	Scaling success
B7	-.205	.756	0.158	Scaling success
B9	-.278	.706	0.158	Scaling success
B10	-.191	.732	0.158	Scaling success
B11	-.036	.671	0.158	Scaling success
B12	-.127	.674	0.158	Scaling success
B13	-.232	.792	0.158	Scaling success

B14	-.232	.782	0.158	Scaling success
B16	-.285	.745	0.158	Scaling success
B19	-.174	.753	0.158	Scaling success
B21	-.256	.745	0.158	Scaling success
B22	-.296	.811	0.158	Scaling success
B24	-.239	.770	0.158	Scaling success

<sup>1</sup> Item own-scale correlations are highlighted.

**Table 13. Preliminary Field Test (49-item reduced CWSv1): Acceptability (N=210)**

Scale	Score range				Floor/ceiling effect		
	% missing	Scale	Sample	Mean (SD)	% Floor	% Ceiling	Skew
CWS Well-Being	16.7	0-128	0-120	53.05 (26.64)	0.5	0	0.34
CWS Support	13.3	0-68	0-51	33.69 (11.15)	0.6	0	-0.44

**Table 14. Preliminary Field Test (49-item reduced CWSv1): Reliability**

Scale	Internal Consistency		
	Item-total correlation range (mean)	Cronbach's alpha	
		<i>n</i>	$\alpha$
CWS Well-Being	0.44-0.77 (0.61)	182	0.95
CWS Support	0.58-0.81 (0.71)	175	0.95

## **4.4 Qualitative Evaluation (Oct 2007)**

The CWS-v1 had space for respondents to comment on the instrument and other issues. This section summarises the feedback we received and how it was used in redrafting the questionnaire.

### **4.4.1 Objectives**

The purpose of the qualitative analysis was to: i. evaluate the acceptability of the new questionnaire to carers and ii. identify and attend to suggestions for improvements and difficulties experienced by respondents in completing the questionnaire.

### **4.4.2 Qualitative Methods**

Of the 210 respondents, 133 (63%) commented in the one-page 'Other comments and feedback' box. These comments were fully transcribed, resulting in a qualitative database of 12,300 words. A simple coding frame was applied:

- comments on Well-Being questions (Part A of the questionnaire)
- comments on Support questions (Part B of the questionnaire)
- comments on Background Information questions
- comments on the content, format and coverage of the questionnaire as a whole.

Our analysis of the data (by Alan Quirk and Sarah Hamilton) focussed on gauging the acceptability of the CWS-v1 to carers and identifying how it might be improved.

### **4.4.3 Results**

#### ***Views on format and coverage of CWS-v1***

Feedback was strongly positive, with positive comments on the layout, wording and coverage of the questionnaire outnumbering negative comments by more than 5 to 1. The analysis did not reveal any major surprises or significant omissions with regard to the domains covered, indicating that the pilot work in Phase 1 had succeeded in producing a questionnaire that measures all important aspects of the carer's experience. The following comments are typical of the positive feedback received:

"This was a very nice form to fill in – well laid-out and clear. I think you have covered everything." [Carer for person with MHP]

"I imagine everyone has a different situation to cope with but on the whole the questions covered lots of angles this ghastly, wicked condition causes." [Carer for person with dementia]

No-one commented that the questionnaire covered *too many* domains, or that it addressed irrelevant issues. On the contrary, numerous comments showed the importance of the issues covered, such as *information and advice* (questions B1 – B10):

"The information and advice for carers from the health service was virtually non-existent. All the information I got was from either a charity or the internet. I received virtually no support from medical/care staff." [Carer for person with MHP]

... the carer's *relationship with the person cared for* (A4 – A9):

"My husband has suffered with Alzheimer's for 7 years. It's been in the last 2 years that he has become aggressive, rude and a bully (I know that he can't help it) but this only happens to me, his 24-hour carer in the privacy of our small 2 bed flat. To everyone else he's a nice man. No-one else knows what it's like to live with him, and I cannot seem to get it over to the CPN [Community Psychiatric Nurse] who visits us." [Carer for person with dementia]

... and the carer's *financial situation* (A14 – A18):

"My mother's nursing home is £650 a week. She is in a later stage of dementia but I do not know how long she will live. I receive Band 2 NHS nursing fund only. Her finances are down to £16K, will the money last? It is not fair that we have to pay so much. Dementia has made her physically frail - bed ridden, doubly incontinent. Why must we all be subject to such worry over finances!!!" [Carer for person with dementia]

While the feedback was mostly positive, some respondents experienced difficulties in completing the questionnaire. We discuss these below.

### ***Difficulties in completing the questionnaire***

Timeframe for well-being questions. For some, the 4-week timeframe for the Well-Being questions (part A of the questionnaire) was too short:

"When the questionnaire arrived I had been away for 5 weeks so it did not apply as none of the questions were within the timeframe." [Carer for person with MHP]

For others it was too long, because a carer's circumstances can change dramatically within this period (e.g. through the person they care for being admitted to hospital or placed in a care home). On balance though, the 4-week timeframe emerged from the analysis as being a reasonable compromise, in that the large majority evidently completed the Well-Being section without difficulty.

That noted, some respondents wanted the opportunity to comment on the *typicality* of the previous four weeks:

"This has been a particularly difficult 4 weeks – I would like the chance to comment that it has not been typical." [Carer for person with dementia]

A small number of respondents did so in the 'Other comments and feedback' box, thus providing useful contextual information for interpreting their responses:

"Our daughter has been in hospital so our replies to questions A34 to A38 do not reflect the situation when she is in the community." [Carer for person with MHP]

Feedback about the Well-Being timeframe led us to conclude that more could be done in the questionnaire to acknowledge that the last four weeks might have been an unusual time for the carer. If not, there is the risk that respondents will answer about a time they regard as being more representative of their caring responsibilities:

"Please note that as my partner only gets ill in periods, I only take care of him in periods. The last relapse is more than 12 months ago, so I have answered the questions based on when he gets unwell." [Carer for person with MHP]

Section 4.4.4 describes how we redrafted the questionnaire to minimise the risk of this occurring.

#### Better suited to carers who live with the person cared for?.

"My mother lives by herself just a few minutes away from where I live and I'm her main carer as she is widowed. I feel the questionnaire is aimed at carers who live with the person they are caring for so my answers may not give the true picture." [Carer for person with dementia]

When the person cared for lives in assisted accommodation or a care home, carers can experience stresses that are not directly addressed by the questionnaire. This perhaps adds to the perception that it is better suited to carers who live with the person they care for:

"Three of us attempt to care for the person with problems. One person sees her almost every day but she stays in [assisted] accommodation, and support is offered there. The questionnaire seems geared to the situation of the person living at the same address. The position we are in is somewhat different – less stressful in some ways but more in others. For instance, when there is friction with other residents, we feel rather helpless to intervene." [Carer for person with MHP]

This feedback alerted us to the need to make the questionnaire more acceptable to carers in such circumstances. Section 4.4.4 describes how we attempted this in the redrafting.

#### ***Respite is a key issue***

"I would love a break. The person I care for won't take a break without me. We can't afford it anyway." [Carer for person with MHP]

The item reduction analyses (4.3.3) resulted in the elimination of all three questions about respite (CWS-v1 questions A29, A30, A31), mainly because too many respondents ticked the 'not applicable' box due to the fact that so few carers access respite. This presented the research team with a problem, because the feedback we received from carers – field trial respondents and participants in the Phase 1 workshops – was that being able to take a break from caring is a key issue, if not the carer's "bug bear":

"No-one helps me look after my husband at home. I do it all myself... Respite care is my bug bear. I am self functioning – so no social workers want to help. Only 2 homes in [my county] take patients who do not need nursing care. He just needs 24 hour care. So I cannot plan a holiday ahead, I have to fit in with what vacancies they have." [Carer for person with dementia]

The feedback we received about respite made it abundantly clear that eliminating any mention of the issue would seriously risk compromising the questionnaire's acceptability to carers. Our solution to this problem is discussed below (4.4.4).

#### **4.4.4 Using Qualitative Results to Revise the CWS**

The qualitative feedback from respondents in the preliminary trial was used in three main ways:

1. We have offered it as evidence for the acceptability of the instrument and its comprehensive coverage of issues that are considered important by carers (4.4.3).
2. When considering the results of the item reduction analyses, we drew on the feedback to inform decisions about which item in a pair of redundant items to eliminate (4.3.3).
3. We revised the instructions page and Background Information section to address the difficulties experienced by respondents (discussed below).

Drawing on the qualitative feedback, we revised the instructions (i.e. the front page) and Background Information section. The aim was to enhance the acceptability of the questionnaire to carers by addressing the difficulties experienced or alluded to by respondents.

In response to comments about the timeframe for Well-Being questions (4.4.3), we added the instruction:

"The first section of the questionnaire asks about how you have been over the past 4 weeks. We recognise that this may have been an unusual time for you. However, we would like you to respond about your well-being in the last 4 weeks specifically. If you would like to tell why this has been an unusual time, there is space to do so at the end of the section."

To counter the perception that the questionnaire was designed only for carers who live with the person cared for (4.4.3), we added:

CWS-v2 question C11:

“Do you live with them at the moment?”

→[Yes/ Some of the time/ No]

“If no, where are they currently living?”

→[Choice of six tick-box response categories]

To ensure that respite was addressed we added a question to the Background Information section to replace items eliminated from the Support scale (4.4.3):

CWS-v2 question C13:

“Which of the following types of support, if any, do you use to allow you to take a break from caring? (Tick more than one box if required.)”

→ [Choice of nine response categories]

In the Phase 1 workshops, participants commented that the original CUES-C questionnaire appears to assume the respondent cares for one person only (not allowing for the fact that a carer for a mother with dementia may also care for a son with schizophrenia). This prompted us to acknowledge in the instructions to the CWS-v1 that “some carers may be caring for more than one person”, and request that respondents choose one answer to each question that “best reflects your caring responsibilities as a whole”. This instruction was retained in the short questionnaire.

In addition we redesigned part of the Background Information section so that respondents were able to answer about their caring responsibilities for up to three people (CWS-v2 questions C9 – C12). The questions were introduced with the following statement, under the heading “About the Person or Persons You Care For”:

“This next section asks about the person or persons you care for with a mental health problem or dementia. Please respond about the person you care for using the first column of boxes (‘Person 1’). If you care for more than one person with a mental health problem or dementia, please tick relevant boxes in the other two columns (Persons 2 & 3). There is space at the end of the questionnaire if you would like to tell us about any further caring responsibilities you may have.”

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## 5 **Phase 3: Final Field Test and Psychometric Evaluation of CWS-v2**

We evaluated the CWS-v2 in a sample of 361 carers for people with MHP or dementia. Participants were recruited from community mental health teams (CMHTs) in two NHS Trusts in the south of England, Rethink and AS services/groups across the country and training courses for carers run by Rethink and AS. Respondents completed the CWS-v2 and validating measures. A sub-sample of carers completed the CWS-v2 a second time after a two-week interval in order to evaluate test-retest reliability. A second sub-sample who had participated in a training course completed a CWS-v2 before and after the intervention to evaluate construct validity. Standard psychometric tests were performed to evaluate acceptability, reliability and validity. Qualitative feedback from respondents was analysed to confirm whether previous changes to the instructions and Background Information section had worked and identify whether any further changes were necessary.

### **5.1 Objectives**

The purpose of this final phase of the study was to carry out a full psychometric evaluation of the reliability and validity of the short (49-item) CWS-v2 in a large independent sample of carers.

### **5.2 Sampling, Recruitment and Questionnaire Administration (Dec 2007 – Apr 2008)**

Participants were recruited from three sources: i. CMHTs in two NHS Trusts in the south of England; ii. Rethink and AS services/groups across the country and iii. training courses for carers run by Rethink and AS (details below). All respondents were entered into a prize draw.

Questionnaires were administered in the same order for all participants. Respondents completed the 49-item CWSv2, then answered demographic and background questions, followed by two validating measures, i.e. the Involvement Evaluation Questionnaire (IEQ; van Wijngaarden 2003) and the General Health Questionnaire (GHQ-12; Goldberg & Williams, 1988). In addition, two global questions about general Well-Being and Support were included to further evaluate validity. At the end of the Well-Being and Support sections of the CWSv2, respondents were asked, respectively, "Overall, how would you rate your general well-being during the past 4 weeks?" (5-point scale; 4=*Excellent*, 3=*Very good*, 2=*Good*, 1=*Fair*, 0=*Poor*) and "Overall, how satisfied are you with the support you receive to help you in your role as a carer?" (4-point scale; 3=*Very satisfied*, 2=*Somewhat satisfied*, 1=*Somewhat dissatisfied*, 0=*Very dissatisfied*). Due

to an administrative error, the last response option for the global well-being question (0=*Poor*) was inadvertently omitted from the questionnaire. Therefore, when undertaking validity analyses involving this question, we dichotomised responses to this question into respondents who rated their overall well-being as being either *Excellent/Very good/Good* or *Fair*.

### 5.2.1 NHS Trusts

A total of 119 questionnaire packs were distributed through specialist mental health services in two NHS trusts in the south of England. To gain access, we first approached team managers in the two Trusts to see if they would be willing to participate. We then attended staff meetings to explain the study and identify volunteers among staff to help with recruitment.

Carers were recruited via care co-ordinators, who typically have a caseload of approximately 30 patients (not all of whom will have an identifiable carer). Participating care co-ordinators were asked to: i. list patients on their current caseload who have a carer; ii. exclude carers whose inclusion might jeopardise their relationships with the patient or care coordinator, or who was otherwise deemed to be inappropriate and iii. find out the postal addresses of eligible carers from their records.

A member of the research team (Alan Quirk) visited each trust to supervise the selection of participants and post questionnaires from trust premises. Using a procedure similar to the one used in the preliminary trial (4.2), a list was made of the unique identifiers and corresponding participants. These lists were stored at the trusts; no personal information was retained by the research team.

The questionnaire pack comprised the CWS-v2 and two validating measures: the GHQ-12 and the IEQ-EU. A copy of the questionnaire pack is shown in Appendix 5. The questionnaires were posted to all carers listed by participating care coordinators. The mail-out envelope also contained a covering letter (Appendix 8), a participant information sheet (Appendix 9), and a postage-paid envelope for returning the completed questionnaire. After an interval of approximately two weeks, we revisited the trusts to send out reminder letters to non-respondents.

### 5.2.2 Rethink and AS Services

The sampling and recruitment procedure was the same as that used for the preliminary field trial (4.2), the only difference being that more services/groups were involved. Recruitment through AS services was achieved through Alan Quirk working closely with AS Senior Policy Officer Louise Lakey.

We posted CWS-v2 questionnaires to 822 carers randomly selected from the caseloads of nine AS branches and 11 Rethink services or carer support groups across England. Between 5 and 90 questionnaires were distributed through each service/group, depending on size of caseload. 470 CWS-v2 questionnaires were distributed as part of a questionnaire pack that was

identical to the one posted to participants recruited through the NHS (see above). To evaluate test-retest reliability, a further 352 questionnaires were posted to carers who were asked to complete a baseline CWS (not the full questionnaire pack) and a second CWS after an interval of 14 days.

### 5.2.3 Training Courses for Carers

To generate data to evaluate construct validity, we recruited a sub-sample of carers who were about to receive an intervention - an education and training programme for carers - run by either Rethink or AS. Participants were asked to complete a CWS-v2 before the course started and one after it had finished.

#### *The Rethink intervention*

The Rethink intervention is a carers' education programme called CETP (Carers Education and Training Programme). The course runs weekly for a total of 11 weeks and is typically attended by 10-12 carers. The topics covered overlap with CWS domains, and include: *information about mental illness, coping with positive and negative symptoms, adjusting to loss, managing stress, impact on the family, the recovery process, working with professionals, coping in a crisis and looking after your self*. The programme was designed by Rethink and is run regularly across the country. Although CETP has not been independently evaluated, it has received positive feedback from carers who have received the training previously and is believed to have a positive impact on carer well-being. Rethink's own internal evaluations found significant improvements measured using the GHQ-12, Family Distress Scale and Understanding Schizophrenia Scale.

Considerable research has been conducted into the effect of psycho-educational interventions for carers, and studies have shown significant improvements in carer burden for carers of patients with mental illness. Magliano (1997) found that psycho-educational interventions, providing help to develop positive coping mechanisms and support from a social network, reduced caregiver burden. Pakenham (1987) similarly found that burden, anxiety, depression and family conflict were all reduced and knowledge of schizophrenia increased. These findings are supported by other studies (Abramowitz & Coursey, 1989; Roick, 2006). Szmukler (1995) found that an intervention with elements of counselling and covering coping strategies, produced positive effects in the carer's relationship with the person cared for and in their understanding of the patient's condition. Education programmes have been shown to help carers acquire and retain information and to provide more effective care (McGill, 1983).

Five CETP courses were run during the course of the final field trial (December 2007 to April 2008), three of which participated in the study.

Identifying and recruiting participants. Carers are recruited onto CETP through Rethink's carer support services and NHS referral. Prior to attending CETP, a carers' suitability for inclusion on the course is assessed, either by one-to-one interview or in an open session led by the CETP co-

ordinators. Open sessions were attended by a member of the research team (Sarah Hamilton) who informed carers about the study. Where assessments were conducted one-to-one, the staff who carried out the assessment informed carers that a study was taking place. Carers were given the participant information sheet and covering letter, but were not at this stage recruited or asked for their consent; this was subsequently elicited by post to avoid any feelings of coercion. The information sheet explained the purpose of the study and that the data collected would also give an indication, though not definitive evidence, as to the effectiveness of the education intervention. It was made clear to the carers that they did not have to take part in the study, and that their choice either way would not affect the intervention they receive. The information included contact details for members of the research team in case carers had any questions about the study.

Data collection. Carers confirmed as taking part in CETP were posted a further covering letter plus a CWS-v2 and consent form (Appendix 10). Participants were asked to complete the form and questionnaire before attending the first training session, and to return them to the research team. Following the final session of the course, 11 weeks later, carers were given a second CWS-v2. They were asked to complete and return it in a postage-paid envelope. Only carers who completed the CETP course were asked to do this. Respondents' questionnaires were coded with a matching unique identifier; this made it possible to link individuals' pre- and post-intervention questionnaires.

### ***The AS intervention***

The Alzheimer's Society runs an intervention similar to the Rethink course described above. It is a 10-12 week Carer Education/Support group, the main difference being that it is specifically for carers for people with dementia. We followed the same recruitment procedures as described above. Three AS courses were run during the period of the field trial, two of which took part in the study.

## ***5.3 Final Field Test: Psychometric Evaluation of Short (49-item) CWSv2 (May – July 2008)***

### **5.3.1 Objectives**

The purpose of this final stage of psychometric analyses, undertaken by Sarah Smith and Donna Lamping, was to carry out a full psychometric evaluation of the reliability and validity of the short (49-item) CWSv2 in a large independent sample of carers.

### 5.3.2 Psychometric Methods

#### *Psychometric evaluation of short (49-item) CWSv2*

Table 15 summarises the psychometric tests and criteria we used in the final field test. These analyses included an examination of:

- item-level performance (missing data, endorsement frequencies, item redundancy)
- acceptability (missing data, floor/ceiling effects, skew)
- reliability (internal consistency, test-retest)
- validity (convergent/discriminant, known groups)
- evaluation of subscales (factor analysis, item convergent/discriminant validity).

#### *Concurrent psychometric evaluation of IEQ and GHQ*

We also conducted a limited concurrent psychometric evaluation of the two validating measures (GHQ and IEQ) to check their psychometric properties in our sample. We used the same tests and criteria described above to evaluate missing data and endorsement frequencies at the item level and acceptability (missing data, floor/ceiling effects, skew) and reliability (internal consistency) at the scale level.

### 5.3.3 Results

#### *Response rates and respondent characteristics*

Completed CWS-v2 questionnaires were returned by 361 carers of people with a mental health problem or dementia (36% response rate). This includes 54 questionnaires (45% response rate) from the two NHS trusts, 279 questionnaires (34% response rate) from the Rethink and AS caseload samples, and 28 questionnaires (53% response rate) from the Rethink and the AS training courses.

In the test-retest sub-sample, 95 completed retest questionnaires were returned by carers who returned the initial test questionnaire (81% response rate). In the pre-post training intervention sub-sample, 22 completed post-intervention questionnaires were returned by carers who returned the pre-intervention questionnaire (79% response rate). Of the 50 carers who started the training intervention, 22 (44%) completed both pre- and post-training questionnaires.

Respondent characteristics are shown in Table 16.

**Table 15. Psychometric Tests and Criteria**

	<i>Psychometric test/analysis</i>	<i>Criterion for retention/hypothesis tested</i>
<b>Item level analyses</b>	Missing data	≤5%
	Maximum endorsement frequencies (floor/ceiling effects)	≤80%
	Item redundancy (inter-item correlations)	≤0.75
	Internal consistency (item-total correlations)	≥0.40
<b>Scale level analyses</b>		
Acceptability	Missing data	≤5%
	Floor/ceiling effects	≤10%
	Skew	-1.00 to 1.00
Reliability	Internal consistency (Cronbach's alpha) Internal consistency (item-total correlations) Test-retest reliability (intra-class correlations)	≥0.70 ≥0.40 ≥0.70
Validity (within scale analyses)	Factor analysis (using principal axis factoring, varimax rotation, with criteria for elimination applied to 2-factor model). In the final field test, 2 factors were requested.	≥0.40 on all factors and/or loading ≥ 0.40 on more than one factor with a difference between loadings <0.20
	Item convergent and discriminant validity analyses (item own-scale vs. item other-scale correlations)	"definite" or "probable" scaling success <sup>Ware et al.,1997</sup>
Validity (between scale analyses)	Convergent validity	i) CWS Well-Being scores will be moderately correlated with GHQ-12 scores ii) CWS Well-Being scores will be moderately correlated with IEQ scores iii) CWS Well-Being and Support scores will be higher for respondents who report better well-being and higher (satisfaction with) support on global questions about well-being and support, respectively
	Discriminant validity	CWS Well-Being and Support scores will be uncorrelated with carers' age and gender
	Known groups differences validity	i) carers who spend ≥50 hours/week providing care will

		<p>report lower CWS Well-Being than carers who spend &lt; 50 hours/week providing care</p> <p>ii) carers who live with the person they care for will report lower CWS Well-Being than carers who do not live with the person they care for</p> <p>iii) carers who are the main carer will report lower CWS Well-Being than carers who are not the main carer</p> <p>iv) after the training intervention, carers will report higher CWS Well-Being and (satisfaction with) Support</p>
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**Table 16. Respondent Characteristics**

Variable		Final field test (N=361)
Age of carer	Mean (SD) Range (n)	65.5 (13.1) 26-102 (345)
Gender of carer	Male (%) Female (%)	123 (34.7) 231 (65.3)
Ethnicity of carer	White (%) Mixed (%) Asian or Asian British (%) Black or Black British (%) Chinese or other ethnic group (%)	335 (92.8) 3 (0.9) 6 (1.7) 7 (2) 3 (0.9)
Relationship with the person cared for <sup>1</sup>	Son/daughter Partner/spouse Brother/sister Parent Friend Other	116 194 6 55 6 8

***Psychometric evaluation of short (49-item) CWSv2***

Imputation of missing data. Initial analyses showed a higher than criterion level of missing data for both the Well-Being (16.6%) and Support (16.1%) scales. Therefore, for all scale-level analyses (or analyses involving scale scores), we followed standard practice and imputed missing data using well-established methods (Ware et al., 1993, 1994). That is, for respondents who answered at least 50% of items on either scale, we imputed data for every missing item on that scale using a person-specific mean calculated on the basis of the mean score of non-missing values for that respondent. We did not impute missing data for respondents who answered <50% of items on either scale. All item-level analyses were, by definition, carried out on non-imputed data.

As a form of sensitivity analyses, we also carried out all psychometric analyses on non-imputed data. Results of these analyses (not reported here) provided similar results to the main analyses on imputed data, and confirmed the psychometric properties of the short (49-item) CWSv2.

Item-level performance. Item-level analyses on non-imputed data showed that items in the Well-Being scale met the criteria for missing data and showed no floor/ceiling effects (Table 17), but that missing data exceeded 5% for four items on the Support scale (B12, B13, B15, B17).

**Table 17. Final Field Test (49-item CWSv2): Missing Data, Endorsement Frequencies**

<b>CWS Well-Being</b>	<b>Items failing criterion<sup>1</sup></b>
Missing data $\leq 5\%$	None
Maximum endorsement frequencies $\leq 80\%$	None
<b>CWS Support</b>	
Missing data $\leq 5\%$	B12 (6.6%), B13 (6.1%), B15 (5.3%), B17 (5.3%)
Maximum endorsement frequencies $\leq 80\%$	None

<sup>1</sup> Non-imputed data

Analyses of inter-item correlations (Table 18) showed an unexpectedly high level of item redundancy in both scales, but even more so in the Support scale (correlations  $>0.75$  for four items in the Well-Being scale (A7/A8; A12/13; A21/A22; A19/A20) and 14 items in the Support scale (B1/B2; B5/B6; B6/B7; B6/B8; B9/B10; B11/B12; B11/B13; B11/B14; B11/B16; B13/B14; B13/B16; B14/B16; B15/B16; B16/B17).

**Table 18. Final Field Test (49-item CWSv2): Inter-Item Correlations**

Item	Inter-Item Correlation <sup>1</sup>
CWS Well-Being	
A7/A8	0.80
A12/13	0.78
A21/A22	0.76
A19/A20	0.82
<b>CWS Support</b>	
B1/B2	0.81
B5/B6	0.79
B6/B7	0.75
B6/B8	0.76
B9/B10	0.82
B11/B12	0.78
B11/B13	0.77
B11/B14	0.76
B11/B16	0.76
B13/B14	0.79
B13/B16	0.75
B14/B16	0.82
B15/B16	0.79
B16/B17	0.82

<sup>1</sup> Imputed data

Acceptability. Both scales met all acceptability criteria; missing data, floor/ceiling effects and skew were all within the acceptable range (Table 19).

**Table 19. Final Field Test (49-item CWSv2): Acceptability (N=361)**

Scale	Score range				Floor/ceiling effect		
	% missing	Scale	Sample	Mean (SD)	% Floor	% Ceiling	Skew
CWS Well-Being	1.1	0-128	6-127	72.23 (29.16)	0	0	-0.10
CWS Support	1.7	0-68	0-51	33.23 (12.574)	0.8	0	-0.58

Reliability - internal consistency. Both scales showed high internal consistency (Table 20). All item-total correlations exceeded 0.40 (Table 21).

**Table 20. Final Field Test (49-item CWSv2): Reliability**

Scale	Internal Consistency		Cronbach's alpha		Test-retest
	Item-total correlation range (mean)	<i>n</i>	<i>α</i>	<i>n</i>	<i>r</i> <sup>1</sup>
CWS Well-Being	0.48-0.83 (0.64)	357	0.96	91	0.92
CWS Support	0.71-0.86 (0.78)	355	0.97	92	0.88

<sup>1</sup> Intra-class correlation**Table 21. Final Field Test (49-item CWSv2): Item-Total Correlations (N=355-357)**

CWS Well-Being	Corrected item-total correlation	Alpha if item deleted
Time to yourself (A1)	.635	.959
Own needs ahead (A2)	.664	.959
Not able to take a break (A3)	.688	.959
Not able to plan for future (A4)	.635	.959
Not able to continue caring (A5)	.488	.960
Strains person care for (A6)	.644	.959
Too dependent now (A7)	.642	.959
Too dependent in future (A8)	.635	.959
Saying things upset you (A9)	.582	.959
Irritable (A10)	.643	.959
Breaking point (A11)	.785	.958
strains family and friends (A12)	.706	.959
drifting apart (A13)	.679	.959
isolated and lonely (A14)	.757	.958
Not getting support (A15)	.623	.959
own financial situation (A16)	.536	.960
financial person care for (A17)	.477	.960
extra costs (A18)	.555	.960
own physical health (A19)	.703	.959
caring make health worse (A20)	.773	.958
constant anxiety (A21)	.833	.958
Depressed (A22)	.733	.958
nothing positive (A23)	.691	.959
lack of sleep worry (A24)	.696	.959
lack of sleep kept awake (A25)	.568	.959
So exhausted can't function (A26)	.773	.958

being treated differently (A27)	.561	.959
accidentally at risk (A28)	.542	.960
aggressive or threatening (A29)	.601	.959
Harming selves (A30)	.532	.960
dangerous situations (A31)	.608	.959
Relapsing (A32)	.602	.959
<b>CWS Support</b>		
enough info on condition (B1)	.798	.964
enough info condition develop (B2)	.738	.965
can get info needed (B3)	.786	.964
easy to understand (B4)	.711	.965
amount of advice (B5)	.819	.964
clear who to go to (B6)	.816	.964
clear in an emergency (B7)	.731	.965
clear routine enquiry (B8)	.767	.965
involvement important decisions (B9)	.752	.965
Influence decisions (B10)	.727	.965
easy to get help person care for (B11)	.859	.963
easy to get help for self (B12)	.795	.964
quality of help person care for (B13)	.809	.964
relationships key staff (B14)	.815	.964
staff communicating (B15)	.763	.965
how seriously staff take what you say (B16)	.819	.964
level of understanding staff (B17)	.758	.965

Reliability – test-retest. Both scales showed good test-retest reliability (Table 20).

Convergent validity. All convergent validity hypotheses were supported. The Well-Being scale showed a moderately high correlation with the GHQ-12 and IEQ (Table 22). Well-Being and Support scores were significantly higher for respondents who reported better well-being and higher satisfaction on the respective global items (Table 23).

**Table 22. Final Field Test (49-item CWSv2): Convergent and Discriminant Validity (Continuous Measures)**

	CWS Well-Being		CWS Support	
	<i>n</i>	<i>r</i> <sup>1</sup>	<i>N</i>	<i>r</i> <sup>1</sup>
<b>Convergent Validity</b>				
GHQ-12	194	-0.66	--	--
IEQ	122	-0.70	--	--
<b>Discriminant Validity</b>				
Age of carer	342	0.14	341	0.21

<sup>1</sup> Pearson correlation

**Table 23. Final Field Test (49-item CWSv2): Convergent and Discriminant Validity (Binary Measures)**

	<i>n</i>	Mean (SD)	<i>t</i> ( <i>df</i> )	<i>p</i>
<b>Convergent Validity</b>				
CWS Well-Being with global well-being <sup>1</sup>				
Fair	158	54.98 (24.83)		
Good/Very good/Excellent	189	86.68 (24.63)	-11.90 (345)	<0.01
CWS Support with global satisfaction with support				
Dissatisfied/Very dissatisfied	97	18.84 (9.60)		
Satisfied/Very satisfied	242	38.85 (8.40)	-19.01 (337)	<0.01
<b>Discriminant Validity</b>				
CWS Well-Being with gender				
Female	229	69.96 (29.56)		
Male	121	77.23 (27.81)	-2.23 (348)	0.03
CWS Support with gender				
Female	227	32.13 (12.79)		
Male	123	35.49 (11.72)	-2.41 (348)	0.02

<sup>1</sup> Due to an administrative error, a response category ("poor") was omitted on the questionnaire; this variable was therefore coded as "fair" vs. "excellent/very good/good".

Discriminant validity. Both Well-Being and Support scales showed good discriminant validity with respect to being uncorrelated with age (Table 22). However, both scales were associated with gender, with men reporting higher well-being and satisfaction with support (Table 23).

Known groups differences validity. Results provided strong support for known groups validity; all except one of the hypotheses with respect to known groups differences (Table 24) were confirmed. Tests of differences between groups showed that: i) carers who spent more than 50 hours/week providing care had significantly lower Well-Being scores than carers who spent < 50 hours/week providing care ( $p < 0.05$ ); ii) carers who lived with the person they cared for had significantly lower Well-Being scores ( $p < 0.05$ ); and iii) carers who were the main carer had significantly lower Well-Being scores ( $p < 0.05$ ). After training, carers had significantly higher (satisfaction with) Support scores ( $p < 0.01$ ), but there was no significant improvement in Well-Being scores.

**Table 24. Final Field Test (49-item CWSv2): Known Groups Validity**

Validating Measure	<i>N</i>	Mean (SD)	<i>t</i> ( <i>df</i> )	<i>p</i>
CWS Well-Being with hours spent caring				
Less than 50 hours/week	133	78.54 (29.02)		
50 or more hours/week	166	67.44 (27.41)	-3.39 (297)	<0.01
CWS Well-Being with whether living with person <sup>1</sup>				
No	89	81.16 (29.16)		
Yes/Sometimes	264	69.17 (28.69)	-3.39 (351)	<0.01
CWS Well-Being with whether main carer <sup>2</sup>				
No	47	89.24 (25.49)		
Yes	303	69.71 (28.88)	-4.38 (348)	<0.01
CWS Well-Being pre-post training intervention				
CWS Well-Being pre-intervention	20	76.72 (26.84)		
CWS Well-Being post-intervention	20	77.24 (26.35)	-0.20 (19)	0.85
CWS Support pre-post training intervention				
CWS Support pre-intervention	19	32.93 (12.38)		
CWS Support post-intervention	19	38.59 (12.49)	-4.64 (18)	<0.01

1 Variable coded as living with any of the people you care for vs. not living with any of the people you care for.

2 Variable coded as being the main carer for any of the people you care for vs. not being the main carer for any of the people you care for.

Evaluation of subscales. Results of factor analysis and item convergent/discriminant analyses support both scales. The final two factor model confirmed that items were correctly grouped into subscales. All Well-Being items and Support items loaded  $>0.4$  on factors 1 and 2, respectively, there were no cross-loading items and the model accounted for 50.8% of the variance (Table 25). Item convergent/discriminant analyses classified items in both scales as definite scaling successes (Table 26).

**Table 25. Final Field Test (49-item CWSv2): Factor Loadings (N=351)**

<b>CWS Well-Being</b>	<b>Factor 1</b>	<b>Factor 2</b>	Note: Factor loadings $\geq 0.40$ are highlighted
Time to yourself (A1)	.644	.115	
Own needs ahead (A2)	.670	.092	
Not able to take a break (A3)	.696	.079	
Not able to plan for future (A4)	.619	.151	
Not able to continue caring (A5)	.486	.063	
Strains person care for (A6)	.645	.125	
Too dependent now (A7)	.652	.063	
Too dependent in future (A8)	.633	.133	
Saying things upset you (A9)	.588	.093	
Irritable (A10)	.652	.096	
Breaking point (A11)	.785	.180	
Strains family and friends (A12)	.687	.272	
Drifting apart (A13)	.664	.222	
Isolated and lonely (A14)	.753	.165	
Not getting support (A15)	.609	.187	
Own financial situation (A16)	.526	.108	
Financial person care for (A17)	.460	.181	
Extra costs (A18)	.555	.075	
Own physical health (A19)	.694	.169	
Caring make health worse (A20)	.774	.158	
Constant anxiety (A21)	.835	.179	
Depressed (A22)	.745	.148	
Nothing positive (A23)	.705	.090	
Lack of sleep worry (A24)	.701	.117	
Lack of sleep kept awake (A25)	.596	-.032	
So exhausted can't function (A26)	.781	.129	
Being treated differently (A27)	.544	.160	
Accidentally at risk (A28)	.565	-.037	

Aggressive or threatening (A29)	.615	.019
Harming selves (A30)	.536	.058
Dangerous situations (A31)	.618	.049
Relapsing (A32)	.594	.142
<b>CWS Support</b>		
Enough info on condition (B1)	.185	.792
Enough info condition develop (B2)	.142	.737
Can get info needed (B3)	.102	.793
Easy to understand (B4)	.153	.706
Amount of advice (B5)	.085	.831
Clear who to go to (B6)	.117	.821
Clear in an emergency (B7)	.150	.725
Clear routine enquiry (B8)	.120	.766
Involvement important decisions (B9)	.114	.766
Influence decisions (B10)	.098	.732
Easy to get help person care for (B11)	.114	.877
Easy to get help for self (B12)	.188	.788
Quality of help person care for (B13)	.105	.821
Relationships key staff (B14)	.093	.827
Staff communicating (B15)	.147	.772
How seriously staff take what you say (B16)	.119	.823
Level of understanding staff (B17)	.194	.753

**Table 26. Final Field Test (49-item CWSv2): Item Own-Scale vs. Item Other-Scale Correlations (N=351)**

Item (number)	CWS Well-Being <sup>1</sup>	CWS Support <sup>1</sup>	2SE (2(1/√n))	Scaling status
Time to yourself (A1)	.635	.219	0.107	Scaling success
Own needs ahead (A2)	.664	.200	0.107	Scaling success
Not able to take a break (A3)	.688	.192	0.107	Scaling success
Not able to plan for future (A4)	.635	.250	0.107	Scaling success
Not able to continue caring (A5)	.488	.143	0.107	Scaling success
Strains person care for (A6)	.644	.226	0.107	Scaling success
Too dependent now (A7)	.642	.168	0.107	Scaling success
Too dependent in future (A8)	.635	.237	0.107	Scaling success
Saying things upset you (A9)	.582	.196	0.107	Scaling success
Irritable (A10)	.643	.201	0.107	Scaling success
Breaking point (A11)	.785	.304	0.107	Scaling success

Strains family and friends (A12)	.706	.369	0.107	Scaling success
Drifting apart (A13)	.679	.315	0.107	Scaling success
Isolated and lonely (A14)	.757	.281	0.107	Scaling success
Not getting support (A15)	.623	.272	0.107	Scaling success
Own financial situation (A16)	.536	.187	0.107	Scaling success
Financial person care for (A17)	.477	.246	0.107	Scaling success
Extra costs (A18)	.555	.170	0.107	Scaling success
Own physical health (A19)	.703	.280	0.107	Scaling success
Caring make health worse (A20)	.773	.284	0.107	Scaling success
Constant anxiety (A21)	.833	.307	0.107	Scaling success
Depressed (A22)	.733	.266	0.107	Scaling success
Nothing positive (A23)	.691	.198	0.107	Scaling success
Lack of sleep worry (A24)	.696	.226	0.107	Scaling success
Lack of sleep kept awake (A25)	.568	.069	0.107	Scaling success
So exhausted can't function (A26)	.773	.250	0.107	Scaling success
Being treated differently (A27)	.561	.251	0.107	Scaling success
Accidentally at risk (A28)	.542	.057	0.107	Scaling success
Aggressive or threatening (A29)	.601	.135	0.107	Scaling success
Harming selves (A30)	.532	.146	0.107	Scaling success
Dangerous situations (A31)	.608	.153	0.107	Scaling success
Relapsing (A32)	.602	.244	0.107	Scaling success
Enough info on condition (B1)	.319	.798	0.107	Scaling success
Enough info condition develop (B2)	.268	.738	0.107	Scaling success
Can get info needed (B3)	.241	.786	0.107	Scaling success
Easy to understand (B4)	.274	.711	0.107	Scaling success
Amount of advice (B5)	.225	.819	0.107	Scaling success
Clear who to go to (B6)	.256	.816	0.107	Scaling success
Clear in an emergency (B7)	.271	.731	0.107	Scaling success
Clear routine enquiry (B8)	.246	.767	0.107	Scaling success
Involvement important decisions (B9)	.245	.752	0.107	Scaling success
Influence decisions (B10)	.224	.727	0.107	Scaling success
Easy to get help person care for (B11)	.261	.859	0.107	Scaling success
Easy to get help for self (B12)	.314	.795	0.107	Scaling success

Quality of help person care for (B13)	.244	.809	0.107	Scaling success
Relationships key staff (B14)	.230	.815	0.107	Scaling success
Staff communicating (B15)	.267	.763	0.107	Scaling success
How seriously staff take what you say (B16)	.254	.819	0.107	Scaling success
Level of understanding staff (B17)	.315	.758	0.107	Scaling success

1 Item own-scale correlations are highlighted.

### ***Concurrent psychometric evaluation of IEQ and GHQ***

IEQ. Item-level analyses indicated that missing data exceeded 5% for 13 of the 27 IEQ items (IEQ2, IEQ6, IEQ7, IEQ8, IEQ9, IEQ10, IEQ11, IEQ13, IEQ16, IEQ17, IEQ18, IEQ20, IEQ24). One item failed the criterion for maximum endorsement frequencies (IEQ 11).

Analyses at the scale level (Table 27), showed a very high level of missing data for the IEQ (43.5%). This is because the IEQ can only be administered and validly scored for carers who have at least 1 hour contact per week with the person for whom they provide care; in our sample, 49 carers (23%) either did not report how long they spent caring or spent less than 1 hour per week and could not be scored on the IEQ. Eliminating these carers still leaves a high proportion (20.5%) of missing data. Floor and ceiling effects and skew were all acceptable, and the IEQ showed good internal consistency (Cronbach's  $\alpha=0.91$ ).

**Table 27. Final Field Test: Descriptive Statistics for Validating Measures**

Validating Measure			Score range			Floor/ceiling effect		
	N	% missing	Scale	Sample	Mean (SD)	% floor	% ceiling	Skew
IEQ	216	43.5	0-108	8-88	38.08 (17.50)	0	0	0.50
GHQ	216	9.7	0-12	0-12	3.87 (3.98)	32.3	3.6	0.64
Global well-being	361	3	1-4	1-4	1.73 (0.80)	45.4	3.1	0.90
Global support	361	5.5	0-3	0-3	1.91 (0.93)	9.7	29.6	-0.56
Age of carer	362	4.7	--	26-102	65.5 (13.05)	--	--	-0.32

Validating Measure	% missing	Frequencies (%)
Gender	1.9	
Female		231 (65.3)
Male		123 (34.7)
Global well-being	3.0	
Fair		159 (45.4)
Good/Very good/Excellent		191 (54.6)
Global support	5.5	
Dissatisfied/Very dissatisfied		97 (28.4)
Satisfied/Very satisfied		244 (71.6)
Time spent caring	16.1	
Less than 50 hours/week		135 (44.6)
50 or more hours/week		168 (55.4)
Main carer	1.9	
No		48 (13.6)
Yes		306 (86.4)
Living with person	1.1	
No		91 (25.5)
Yes/Sometimes		266 (74.5)

GHQ. Item-level analyses indicated that missing data exceeded 5% for 1 of the 12 items (GHQ3). No items failed the criterion for maximum endorsement frequencies.

Analyses at the scale level (Table 27), showed a higher than expected level of missing data for the GHQ (9.7%). Ceiling effects and skew were acceptable, though floor effects exceeded the criterion. The GHQ showed good internal consistency (Cronbach's  $\alpha=0.92$ ).

Descriptive statistics for the other validating measures are presented in Table 27. Missing data were relatively high for the time spent caring variable (16.1%). Floor effects were evident for the global Well-Being item, and ceiling effects for the global Support item.

## ***5.4 Qualitative Evaluation (July 2007)***

The CWS-v2 had space for respondents to comment on the instrument and other issues. This section summarises the feedback we received, and how it was used in redrafting the questionnaire.

At this stage in the project, we were limited in how we could use the feedback because the Well-Being and Support sections of the questionnaire were fixed. Indeed, only a few tweaks to the wording of the instructions and Background Information section resulted from our analysis of the feedback (see 5.4.4).<sup>4</sup>

### **5.4.1 Objectives**

The purpose of the qualitative analysis was to: i. check whether respondents experienced difficulties with the revised instructions page and background information questions (4.4.4) and ii. identify and attend to any new difficulties or suggestions for improvements.

### **5.4.2 Qualitative Methods**

All free-text responses in 'Other Comments and Feedback' boxes were read and selectively transcribed (general comments unrelated to the questionnaire were not typed-up). Particular attention was paid to notes made by respondents elsewhere on the questionnaire as these were often very revealing. For example, respondents sometimes explained why they had answered as they did (e.g. ticking two boxes in response to a single question, or offering no response), and on one occasion the respondent edited the question to make it suitable for her circumstances, and then ticked the box. All such ad hoc comments were transcribed and analysed.

Comments from 167 of the 361 respondents (46%) were transcribed, resulting in a qualitative database of 9,700 words. The coding frame used

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<sup>4</sup> See also Appendix 6 which shows the final version of the questionnaire; that is, the CWS-v2, revised with track changes.

in the preliminary trial (4.4.2) was applied to the data. The analysis focused on identifying difficulties experienced by respondents in completing the questionnaire.

### 5.4.3 Results

#### *Difficulties in completing the questionnaire*

Question C7. Respondents commented on how difficult it can be to estimate the number of hours they had spent caring last week. One respondent, who answered that it had been “40 hours”, added:

“How do you quantify this when it’s a care of being there with an ear cocked, rather than doing any actual ‘caring’ for quite a lot of the time? My mother is never left on her own in the house for more than a few hours at a time – so does that really make it more like 140 hours a week? The questions are rhetorical!” [Carer for person with dementia]

Such feedback indicates that responses to this question need to be interpreted with caution because they may underestimate the demands of an individual’s caring role. It also helps to account for the high level of missing data for this question (16.1%; see 5.3.3).

Question C11. A single comment written in the margin next to the question “Do you live with them at the moment?” suggested that its wording could be improved. The carer concerned had ticked ‘Yes’, but clarified: “She lives with me”.

Question C12. The question “Which of the following statements best describes your role as a carer?” attracted criticism for appearing not to allow for “changes and fluctuations in circumstances”. The idea that a carer’s role can be very fluid in response to changing circumstances (e.g. a hospital admission) was first raised by carers in the Phase 1 workshops.

#### *Better suited to ‘primary’ carers?*

One of the attenders at a training course for carers left the whole of Section A blank, explaining:

“It feels inappropriate to answer this section. I’m not the primary carer and so at present am not personally too disrupted by the caring, but want to know more as the primary carer will not attend a course of this nature.” [Carer for person with dementia]

Later, in the ‘Other Comments and Feedback’ box, he reinforced the point by adding: “Feels a bit fraudulent to complete form sections if one is not the primary carer!”

### 5.4.4 Using Qualitative Results to Revise the CWS

To address the difficulties referred to above, we made some small revisions to the final version of the questionnaire (Appendix 7). To maximize the

clinical utility of the instrument, we also added a needs assessment component: Part C "Your Needs".

### ***Instructions page***

To counter the perception that the questionnaire is for 'primary' carers only, we added a new bullet point:

"It [the questionnaire] can be filled in by anyone who has a role in caring for someone with a mental health problem or dementia. You don't have to be a person's main carer or live at the same address as them."

### ***Background Information***

Question C7: To acknowledge the difficulty some carers will have in answering the question, the wording was changed from "Last week, approximately how many hours did you spend looking after someone with a mental health problem/dementia?" to "Please estimate as best you can how many hours you spent last week looking after someone..."

Question C11: The wording was changed from "Do you live with them at the moment?" to "Do you live with each other at the moment?"

Question C12: To convey an understanding of the fluidity of a carer's role, "... at the moment" was tagged to the end of the question "Which of the following statements best describes your role as a carer?"

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## 6 Discussion

### 6.1 Summary

Over three main study phases we deconstructed the original CUES-C and developed and tested a new instrument, called the *Carer Well-Being and Support Questionnaire (CWS)*:

*Phase 1* - the original CUES-C questionnaire was 'deconstructed' and a long 74-item version of the CWS (the CWS-v1) was created.

*Phase 2* - the CWS-v1 was subjected to a preliminary field test, to reduce the number of items and undertake a preliminary evaluation of the psychometric properties of the shorter, item-reduced version of the questionnaire (the CWS-v2).

*Phase 3* - the 49-item CWS-v2 was evaluated in a sample of 361 carers, recruited via the NHS, Rethink and AS services and training courses for carers. Standard psychometric tests were performed to evaluate acceptability, reliability and validity.

Overall, the CWS Well-Being scale shows moderate evidence of acceptability, and good evidence of internal consistency, test-retest reliability, convergent, discriminant and known groups validity. The CWS Support scale shows moderate evidence of acceptability and good evidence of internal consistency and test-retest reliability. The limited evidence of validity for the Support scale is partly due to the lack of appropriate validating measures and/or hypotheses. There is good evidence to support the Well-Being and Support scales as two distinct scales.

The Well-Being and Support scales – CWS Parts A and B respectively - have been designed so that they can be administered separately. The Background Information section (Part D) can be administered after either scale or as the third part of the full CWS (Appendix 7).

### 6.2 Limitations

The following limitations should be considered when reviewing the psychometric evidence:

1. Although a large number of carers were invited to participate in the final field test (N=994), and a high number of questionnaires were returned

(N=361), the response rate was low (36%). It was not possible to evaluate sampling bias as no information was collected on non-responders. Therefore, the representativeness of our sample of respondents, as well as the generalisability of findings to the wider population of carers in the UK, cannot be determined.

2. Recruitment for the two field tests resulted in samples with a low proportion of BME carers. Possibly linked with this, only an English language version of the questionnaire was produced, so non-English speakers will have been excluded.
3. Tests of convergent validity for the CWS Support scale were limited due to: i. the lack of a psychometrically validated instrument measuring a similar construct to use in a head-to-head comparison and ii. the poor psychometric properties of the IEQ-EU in our sample.
4. The evaluation of convergent validity of the CWS Well-Being scale was compromised by an administrative error in which one of the response options for the global question about well-being (item A33) was inadvertently omitted from the questionnaire. Results comparing the Well-Being scale and the global question, although strongly supportive of validity, should be interpreted with caution.
5. The evaluation of known groups validity for the CWS Support scale was limited both by the lack of appropriate and testable hypotheses and the small number of participants in the training intervention sample (n=22).
6. The responsiveness of the CWS has not yet been evaluated, as the current study was not designed to investigate the performance of the CWS before and after a treatment of known efficacy. Conclusions about responsiveness await future research.

### ***6.3 Policy Implications***

The U.K. government is increasingly recognising the contribution made by carers. The 2008 Carers' Strategy includes a commitment that, by 2018, "carers will be respected as expert carer partners and will have access to the integrated and personalised services they need to support them in their caring role", and that "carers will be supported to stay mentally and physically well and treated with dignity" (Department of Health, 2008). These policy commitments make it even more important to establish a solid evidence base on interventions that have been proven to meet carers' needs for support effectively.

Assessing carers' needs is distinct from actually meeting those needs, and the latter is inadequately attempted at present. If used widely, the CWS could strengthen local (and possibly national) attempts to demonstrate why things need to improve in this respect. The strengths of the CWS are its proven validity and reliability, and the scope of domains covered by the tool. It can be used to assess the effectiveness of support services which meet the government commitment, and can also provide a picture of the areas in which needs are not being adequately met.

Although the Carers' Strategy provides a commitment to support carers, it says little about mental health carers specifically, highlighting the lack of understanding about how mental health carers' needs differ from those of other carers.

## ***6.4 Uses of the CWS***

Results derived from CWS can be used at different levels in the statutory sector:

1. Through aggregation at the mental health team level, for the purpose of service planning or for evaluating or monitoring the effectiveness of teams at addressing the problems of carers.
2. Through aggregation at the level of a service, or nationally, for performance management, benchmarking or health services research.

While the instrument has not been validated for use in individual decision-making, it has the potential to be used as a central component of the assessment of an individual carer by mental health and other services. This would be for the purpose of identifying the problems faced by that carer and, subsequently, gauging of the extent to which these problems have been addressed.

Voluntary sector organisations may also find the CWS helpful. Indeed, the CWS and the findings of this project have already been promoted throughout Rethink, as part of an initiative to improve outcome measurement. The CWS has been made available to help structure conversations between Rethink staff and clients and/or for routine assessment of needs and outcomes.

## ***6.5 Future Research and Development***

We conclude by proposing new research and a range of initiatives to encourage and support the adoption and use of CWS. The project team is well placed to develop an implementation programme based on some or all of these initiatives and would welcome the opportunity to develop a proposal.

1. Evaluate the responsiveness of the CWS.
2. Evaluate the feasibility of using the CWS in real-world service settings for the routine assessment of needs and outcomes.
3. Explore the conceptual validity and relevance of CWS in relation to BME communities and consider translation issues.
4. Develop and validate a short version of the CWS.
5. Explore adapting the CWS for use with other carer groups. Preliminary consultation by the research team suggests that the CWS domains may be equally relevant to carers for people with other conditions, such as acquired brain injury or brain tumour, so future work should investigate the appropriateness of use and validity of the CWS in other carer groups.
6. Develop and validate an online version of CWS. This will allow carers to assess their own needs and monitor their well-being and support scores over time. NHS staff could be encouraged to use 'CWS-online' or tell carers about it. We propose that the online version is made widely available, for example through the NHS (e.g. the National Programme for IT) and the websites of the Royal College of Psychiatrists, Rethink and the Alzheimer's Society.
7. Develop a comprehensive resource pack that addresses CWS domains. This will involve: i. compiling the best current information and advice that would enable carers to address problems relating to each domain and ii. undertaking new workshops to access carers' tacit knowledge (e.g. about how to cope in certain situations or gain access to scarce resources). Our Phase 1 workshops were very effective in eliciting such information from experienced carers -- precisely the sort of information that isolated, inexperienced carers are likely to find beneficial if it is disseminated in this way.
8. Develop software for linking CWS-online to an electronic version of the resource pack, so that the responses from a carer completing the questionnaire would automatically direct them to helpful resources. For example, respondents who are "very dissatisfied" with the amount of information they have about the condition/illness of the person they care for (CWS question B1), would be connected or referred to sites where such information can be found (organisations, websites etc).

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## Appendix 1: Development of Original Questionnaire: *Carers' and Users' Expectations of Services – Carers' Version (CUES-C)*

The Carers' and Users' Expectations of Services (CUES) measures were developed as one of a series of studies forming the Department of Health funded Outcomes of Social Care for Adults initiative (OSCA). It was a collaborative project involving The Royal College of Psychiatrists' Research Unit, The Royal College of Nursing Institute, The National Schizophrenia Fellowship (now Rethink) and The University of East Anglia School of Social Work.

The purpose of the project was to develop a tool that would measure outcomes for service users experiencing mental illness and carers of people with mental illness. The project developed two separate instruments which followed a similar structure, one for service users (CUES-U) and one for carers (CUES-C). The project was completed in 1999. The SDO commissioned review of outcomes measures for carers (Harvey et al., 2005) recommended that "studies to establish the psychometric properties of CUES-C [should be] conducted as a matter of urgency."

This appendix describes how CUES-C was originally developed and tested (for further detail, see Lelliott et al., 1999; 2003).

### ***Development of CUES-C***

#### **Developing Domains**

To ensure that the CUES-C addressed those issues of most importance to carers, the first stage of the project was to establish what those issues are. This was done through a literature search and a consultation exercise.

#### ***Literature Review***

Online databases, including Medline, Embase and PsycINFO, were searched for published literature relating to the issues facing carers and existing measurement tools. The resulting literature was then hand searched for additional referenced publications. Experts doing related work were contacted and asked to identify any additional key literature. One hundred and sixty-three articles were identified relating to relevant scales. Grey literature held by a wide range of mental health organisations was also searched to find reports on carers' views about the issues which were most important to them.

### ***Focus Group***

A focus group was held with carers from a carer support group. The group was encouraged to discuss what issues should be included in the new instrument. The group was also asked to consider what possible uses the new measure could have. The analysis of the data from the focus groups was informed by prior knowledge and the information retrieved in the literature review.

### ***Developing and testing domains***

Through analysis of the literature retrieved and the focus group data, a list of provisional domains was created. This list was considered by the research team and, where appropriate, overlapping items were combined.

The provisional domains were tested in the course of telephone interviews with five carers. The interview was semi-structured to elicit views on the identified domains but also allowed interviewees to raise additional issues.

### ***Piloting***

A draft measure was created using the provisional domains and feedback from the interviews. These were turned into statements and questions. In developing the draft measure, particular attention was given to being concise and clear and avoiding overlap or repetition.

The draft measure was piloted with carers identified through Rethink groups. A total of 79 questionnaires were completed and returned through the post, and 15 were completed at group meetings to provide face-to-face feedback.

Data from the pilot were analysed using statistical methods and the feedback was analysed qualitatively. The findings from the pilot were used to revise the tool before it was tested in the field trial.

## **Content and Structure of CUES-C**

### ***Domains of CUES-C***

Table 1 shows how the domains evolved from those identified through the literature review. Following the pilot, the titles of some items were changed and a thirteenth item was added.

**Table a: Development of CUES-C items**

Domains identified through literature	Piloted items following telephone consultation	Final CUES-C items
Inclusion in the care team	<i>Involvement in planning and care</i>	<i>Involvement in planning of treatment and care</i>
Information	<i>Information about mental illness and its effects</i>	<i>Information about mental illness and its effects</i>
	<i>How to get help and advice</i>	<i>How to get help and advice</i>

	<i>Information about the care team</i>	<i>Information about care workers</i>
Relationship with service providers		<i>Support for carers</i>
Services	<i>Quality of services you receive</i>	
Employment	<i>Your own interest and activities</i>	<i>Your own life</i>
	<i>Financial situation</i>	<i>Money</i>
Social and family life	<i>Social and family life</i>	<i>Relationship with the person you care for</i>
		<i>Family and friends</i>
Carers' health	<i>Your wellbeing</i>	<i>Your wellbeing</i>
Risk and safety	<i>Risk and safety</i>	<i>Risk and safety</i>
Prejudice and discrimination	<i>Discrimination</i>	<i>Stigma and discrimination</i>
The end of caring	<i>Choice to care</i>	<i>Choice to care</i>

## Structure of CUES-C

Each item in CUES-C was prefaced with a normative statement. The purpose of these statements was, firstly, to orientate the carer to the issues covered by the question, and, secondly, to set a level of expectation for carers to judge their own situation against. The statements presented the needs and wants of carers as found in the earlier stages of the research project. In part A of each question, carers are asked to rate their own situation in comparison to this statement on a three-point scale. Then, in part B, carers are asked to indicate whether they would like more help, support or information in relation to that item.

## Field Testing CUES-C

The CUES-C was field tested with 243 carers. Of these, 51 were recruited through statutory mental health services, 63 through voluntary sector services, 82 through carers' groups and 47 through Rethink membership. Recruitment took place across England, Wales and Northern Ireland to give wide geographical spread. Ninety-seven carers completed the CUES-C twice at an interval of 2 to 14 days to examine test-retest reliability.

### Results

The mean age of the carers who took part in the field trial was 60 years. About three-quarters were women and 6% were from an ethnic minority. 97% were a spouse or first degree relative of the person they cared for. 70% had been a carer for more than 5 years.

Responses to parts A (where carers are asked to rate their own situation alongside the normative statement) and B (where carers are asked whether they would like more help in this area) questions are summarised in tables 2 and 3 below, reproduced from Lelliott et al. (2003).

**Table b: Responses to CUES-C Part A questions**

Items:	Full satisfaction 0		Partial satisfaction 1		Dissatisfaction 2		Missing	
	N	%	N	%	N	%	N	%
1. How to get help and advice	110	46	114	48	14	6	5	2
2. Information about care workers	82	34	132	55	26	11	3	1
3. Information about mental illness and its effects	89	37	122	51	26	11	2	1
4. Involvement in planning of treatment and care	78	33	105	45	53	22	7	3
5. Support for carers	57	25	126	56	44	19	16	7
6. Your own life	69	30	101	44	61	26	12	5
7. Relationship with the person you care for	89	38	101	43	44	19	9	4
8. Family and friends	118	50	89	38	29	12	7	3
9. Money	116	50	88	38	30	13	9	4
10. Your wellbeing	54	23	144	60	41	17	4	2
11. Stigma and discrimination	149	63	69	29	17	7	8	3
12. Risk and Safety	87	37	108	46	42	18	6	3
13. Choice to care	98	46	58	27	56	26	31	13

Note: Missing data frequencies are not taken into account for the percentage calculations.

**Table c: Responses to CUES-C Part B questions**

Items:	Would like more help 2		Unsure 1		Would not like more help 2		Missing	
	N	%	N	%	N	%	N	%
1. How to get help and advice	155	67	41	18	34	15	13	5
2. Information about care workers	179	79	18	8	31	14	15	6
3. Information about mental illness and its effects	184	79	13	6	35	15	11	5
4. Involvement in planning of treatment and care	152	67	42	19	32	14	17	7
5. Support for carers	154	70	38	17	29	13	22	9
6. Your own life	100	47	51	24	62	29	30	12
7. Relationship with the person you care for	109	48	35	15	83	37	16	7
8. Family and friends	68	31	39	18	111	51	25	10
9. Money	69	31	39	18	115	52	20	8
10. Your wellbeing	114	52	44	20	63	29	22	9
11. Stigma and discrimination	49	24	27	13	128	63	39	16
12. Risk and Safety	92	44	42	20	77	37	32	13
13. Choice to care	43	22	42	21	112	57	46	19

Note: Missing data frequencies are not taken into account for the percentage calculations.

## ***Preliminary Evaluation of CUES-C***

Although the CUES-C did not undergo a full psychometric evaluation as part of the original development study, some very preliminary analyses were undertaken to inform the further development of the measure.

### **Inter-Item Correlations**

Inter-item correlations in Part A were mostly below 0.4, with the exception of 'Your own life' and 'Your wellbeing'. Coefficients in Part B were higher than in part A with 20 having coefficients above 0.4. Correlations between parts A and B were all significant and in the expected direction. They showed that lower satisfaction was associated with the desire for more help. There was however a difference between items 1 to 5 and items 6 to 13. Responses showed that more people expressed dissatisfaction relating to their own lives than wanted help in this area. This was not the case for items relating to direct support for their role as carers (items 1-5).

### **Item Test-Retest Reliability**

The intraclass correlation coefficients for time 1 and time 2 CUES-C completions showed poor item reliability; all but 10 questions in parts A and B had coefficients  $> 0.61$ , whereas the remaining 10 were 0.41 – 0.60.

### **Factor Structure**

A principal components analysis showed that items in Part A broadly fell into 3 factors: i. 'burden of caring' (items 6 to 12); ii. quality of help, support, information and advice provided by services and involvement of carer by services (items 1 to 5) and iii. the extent to which carers feel free to live their own lives (items 6 and 13). The components analysis was similar to that for part A, but finding two factors. Factor one included items 6 to 13 and factor two included items 1 to 5.

### **Acceptability**

During the pilot phase, evidence was collected to show the acceptability to carers. The results showed that 99% of carers found the instructions "clear" or "usually clear"; 48% felt that the CUES-C was comprehensive in covering all the issues important to them (29% did not feel it was comprehensive); 89% felt that the length of the scales was about right; 64% completed the questionnaire in less than 30 minutes.

On the whole, the response rate in the field trial exceeded the expectations of the researchers conducting the study, considering the methods used and the nature of the group involved. Most items had acceptable levels of missing data, though carers were more likely to answer the questions in part A than part B.

## **Limitations**

The main limitation of the original development study was that the CUES-C did not undergo formal psychometric evaluation. While some very preliminary analyses were undertaken to examine some aspects of the performance of the CUES-C at an item level, the reliability and validity of CUES-C scores were not evaluated.

Another limitation in the previous CUES-C work is that the sample was not randomly selected. Never-the-less, the broad findings concerning carer wellbeing and satisfaction with support are supported by other surveys.

One item, item 13 ('Choice to care'), had a high proportion of missing data. This is most likely because of the sensitive nature of this question.

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## Appendix 2: Phase 1 Workshops Topic Guide

### **(1) Introduction**

Remind people what CUES-C is, how it can be used, and why we're doing the project.

### **(2) Any general comments about the questionnaire?**

Ask how people got on with it generally, i.e. whether they thought it worked for them and whether they liked it or not.

#### Prompts

*Was the layout alright?*

*How was the wording?*

*Was anything confusing?*

*Were any important questions missing?*

### **(3) Any problems with it, or with specific questions?**

Find out whether they had any problems with the questionnaire as a whole, or with specific questions, and explore the reasons why.

### **(4) How to improve the 'problem items' identified by our statisticians?**

Some time ago, these questionnaires were filled in by about 300 carers. Our statisticians analysed their responses and found that a few questions needed to be asked differently in order to get to the bottom of what the question was trying to get at. These included questions:

- 7 Relationship with the person you care for
- 12 Risk and safety
- 13 Choice to care

#### Question/Prompts

*Looking at each question in turn.....*

*(a) Can you see any problems with the way it is worded etc*

*(b) If you were speaking with another carer, what extra questions might you ask to find about their views on:*

*Q7: how good, or strained, their relationship is with the person they care for*

*Q12: concerns about their own safety or the safety of the person cared for [definitely 2 questions are needed]*

*Q13: whether they feel they have a choice about whether to continue as a carer.*

## **(5) How to improve how the questionnaire assesses: 'carer wellbeing' & 'carer support'**

We think this questionnaire probably addresses two or three main things: (1) people's general "wellbeing"; (2) how much support they are receiving to help them in their role as a carer for someone with a mental health problem or dementia.

### Question/prompts

*Looking at the list of things that we think make up each of these three 'things' in turn.....*

*(a) If you were speaking to another carer, can you think of anything else you would ask them to find about:*

- how well they are feeling about their life generally*
- how much support they are receiving, and whether they think it's what they need [\*N.B. what about informal support from family and friends?\*]*
- whether they have been discriminated against or stigmatised.*

### Further prompts

*(a) What about questions to get at their morale?*

*(b) What about people's need for emotional support, and 'understanding' of their situation, of rather than just practical help?*

## Appendix 3: Carer Well-Being and Support Questionnaire-v1 (long, 74-item)

For office use only	
Trial ref: _____	Date received: _____
Site ref: _____	Date entered: _____
Ind ref: _____	

### Carer Well-Being & Support

Developing a questionnaire for  
carers of people with  
a mental health problem or dementia

**Before completing this questionnaire, please make sure you have read the enclosed Participant Information Sheet. When you return this questionnaire we will take it to mean that you have read the sheet and consent to take part in the project.**

Thank you for agreeing to help us improve this questionnaire. Before you start filling it in, there are a few things you should know.

- ❖ This questionnaire is for you as a carer to talk about your own circumstances and needs, and not those of the person you care for. We recognise that carers' needs are closely linked with the needs of the person they care for, but this questionnaire has been designed to find out about YOUR circumstances and YOUR needs.
- ❖ Please try to answer every question; there are no wrong or right answers.
- ❖ We recognise that some carers may be caring for more than one person. For each question, **choose one answer** that best reflects your caring responsibilities as a whole.
- ❖ There is a space at the end of the questionnaire for you to mention anything that hasn't already come up.
- ❖ By completing the questionnaire and sending it back to us, you will help us to find out how well it works. We will use your answers to help improve this questionnaire. We are not conducting a survey of carers.

Each questionnaire comes with a POSTAGE PAID envelope so you can send it back when you've finished. If you don't have the envelope, you can still return it to us at the following address:

Alan Quirk  
CUES-C Development Project  
Royal College of Psychiatrists Research & Training Unit  
4<sup>th</sup> Floor, Standon House  
21 Mansell Street  
LONDON E1 8AA

## A. Well-Being

The questions in Part A are about aspects of **your general well-being**. All of the questions are about how you have been over the past four weeks.

We recognise that some carers may be caring for more than one person. For each question, **tick one box on each line** that best reflects your caring responsibilities as a whole.

Please write **today's date**: \_\_\_\_\_

### Your day-to-day life

The first set of questions asks about how your responsibilities as a carer have affected your **day-to-day life**. (Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you that your caring responsibilities stopped you from...	A lot	Quite a bit	Moderately	A little	Not at all
1. having enough time to yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. having a life of your own?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. putting your own needs ahead of the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Your relationship with the person you care for

The next questions are about your **relationship with the person you care for**. (Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
4. strains in your relationship with the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. the person you care for being too dependent on you <u>at the moment</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. the person you care for becoming too dependent on you <u>in the future</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. the person you care for saying things that upset you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. feeling irritable with the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. reaching 'breaking point', where you feel you can't carry on with things as they are?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your relationships with family and friends

(Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
10. strains in your relationships with family and friends, because of your caring responsibilities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. "drifting apart" from family and friends, because your caring responsibilities limit the time available to keep in contact with them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. feeling isolated and lonely because of the situation you are in?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. not getting the support you need from family and friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your financial situation

(Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
14. your own financial situation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. the financial situation of the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. having to cover extra costs of caring (e.g. extra help in the home, trips to hospital)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. having to cover your own living costs (e.g. bills, rent, mortgage)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. getting into debt?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your physical health

(Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
19. your own physical health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. problems with your own physical health making it difficult to properly look after the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. your caring role making your physical health worse?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your emotional well-being

(Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
22. being unable to cope with the "constant anxiety" of caring?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. feeling depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. being unable to see anything positive in your life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. lack of sleep brought about through worry or stress?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. lack of sleep caused by the person you care for keeping you awake at night?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. feeling so exhausted that you can't function properly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Stigma and discrimination

(Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
28. people treating you differently because of the illness/condition of the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. having to keep the illness/condition of the person you care for secret because of how you think other people might react (e.g. neighbours, people at work)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. having to keep the illness/condition of the person secret because he or she doesn't want other people to know about it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. not being able to tell people the real reasons for things (e.g. why you had to miss an appointment), because you don't want people to know about the illness/condition of the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your own safety

(Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about the person you care for...	A lot	Quite a bit	Moderately	A little	Not at all
32. accidentally doing something that puts you at risk (e.g. leaving the gas on)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. being aggressive or threatening towards you (e.g. verbal threats, sexual aggression, physical intimidation)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## The safety of the person you care for

(Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about the person you care for...	A lot	Quite a bit	Moderately	A little	Not at all
34. harming themselves accidentally?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. harming themselves deliberately?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. getting themselves into dangerous situations?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. being unable to cope with difficult situations (e.g. rude shop assistants, street bullies)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. relapsing or deteriorating, such that it puts their safety at risk?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your role as a carer

(Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
39. not being able to continue caring due to reasons beyond your control (e.g. becoming ill yourself, looking after very young children)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. feeling trapped in your role as a carer because there is no alternative to what you are currently doing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. not being able to plan for the future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. not being able to take a break from caring?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. your caring role becoming too demanding?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## B. Support

The questions in Part B ask **how satisfied** you are, in general, with the **support you receive** to help you in your role as a carer.

### Information and advice for carers

The next questions ask about how satisfied you are with **information and advice** for carers. (Please tick one box on each line.)

<u>In general</u> , how satisfied are you...	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
1. that you have enough information about the condition/illness of the person you care for to enable you to feel confident in caring for them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. that you have enough information about how their condition/illness is likely to develop in the longer-term?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. that you can get whatever information you need when you need it (e.g. through your doctor or on your own)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. with how easy it is to understand the information you have?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. with the availability of information in your own language?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. with the amount of advice available to you (e.g. from healthcare workers or other carers)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. that you are clear about who to go to for the information and advice you need?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. that you are clear about who is, or who should be, providing treatment and care to the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. that you are clear about who to contact if there is an emergency and you need help right away?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. that you are clear about who to call if you have a routine inquiry?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your involvement in treatment and care planning

(Please tick one box on each line.)

<u>In general, how satisfied</u> are you with...	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
11. your involvement in important decisions (e.g. medication, hospitalisation)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. your ability to influence important decisions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Support from medical and/or care staff

The following questions ask about **the support you may receive from medical and/or care staff** - that is, the people providing treatment and care for the person you care for (e.g. GPs, social workers, housing support workers, community psychiatric nurses, care workers, psychologists and psychiatrists). (Please tick one box on each line.)

<u>In general, how satisfied</u> are you with...	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
13. how easy it is to get help and support from staff for the <i>person you care for</i> (e.g. to prevent relapse)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. how easy it is to get help and support from staff for <i>yourself</i> (e.g. advice on how to deal with certain behaviours)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. the <u>amount</u> of help and support from staff for the <i>person you care for</i> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. the <u>quality</u> of help and support from staff for the <i>person you care for</i> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. the <u>amount</u> of help and support from staff for <i>yourself</i> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. the <u>quality</u> of help and support from staff for <i>yourself</i> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. your relationships with key staff who support the <i>person you care for</i> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. that you are able to speak with medical/care staff when you need to, either face-to-face or over the phone?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. with how well the staff you have contact with are communicating with each other (i.e. that they share important information)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. with how seriously staff take what you say to them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. with the respect given to you by staff?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
24. with the level of understanding staff have of what it must be like to be in your situation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. with the degree of trust you have in staff to keep things you have told them confidential?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. with your trust in staff to tell you everything you need to know (e.g. risk of self-harm)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. that you can openly express any complaints to staff?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Support from other carers

The next questions ask about the **practical and emotional support you may receive from other carers** (e.g. through a carer support group). (Please tick the 'Not applicable' box if you do not receive support from other carers.)

<u>In general, how satisfied</u> are you with...	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
28. the help and support from other carers? <input type="checkbox"/> Not applicable; I do not receive any support from other carers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Taking a break ('respite')

The questions are about short-term or temporary **respite care that allows you to take a break from caring**. (Please tick one box per line, or the box below the question marked 'Not applicable')

<u>In general, how satisfied</u> are you...	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
29. with how easy it is for you to get respite care locally? <input type="checkbox"/> Not applicable; I have not tried to get respite care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. that good quality respite care is available if you want it? <input type="checkbox"/> Not applicable; I have not tried to get respite care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. with the cost of respite care? <input type="checkbox"/> Not applicable; I have not tried to get respite care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Other comments and feedback

Please use the space below to write down any comments about the questionnaire itself (e.g. layout, appearance, etc.) or whether there is anything we've missed in the questionnaire.

Also, please let us know if you have anything else that's important to you, that you would like help with or that you'd like to change.

## Background information

The following information will help us to better understand your caring situation and interpret your answers more effectively.

**Your date of birth?** \_\_\_\_\_

**Your gender?**

Female ☐

Male ☐

Other ☐

**Your ethnic background?**

*White*

British ☐

Irish ☐

Other White background ☐

please state \_\_\_\_\_

*Mixed*

White and Black Caribbean ☐

White and Black African ☐

White and Asian ☐

Other Mixed background ☐

please state \_\_\_\_\_

*Asian or Asian British*

Indian ☐

Pakistani ☐

Bangladeshi ☐

Other Asian background ☐

Please state \_\_\_\_\_

*Black or Black British*

Caribbean ☐

African ☐

Other Black background ☐

please state \_\_\_\_\_

*Chinese or other ethnic group*

Chinese ☐

Other ☐

please state \_\_\_\_\_

**Your environment (the area where you live)?**

Rural ☐

Semi-urban ☐

Urban ☐

**Your relationship with the person you care for?**

**Parent** of the person you care for? ☐

**Partner/spouse** of the person you care for? ☐

**Brother/sister** of the person you care for? ☐

**Son/daughter** of the person you care for? ☐

**Friend** of the person you care for? ☐

**Other** (please specify below) ☐

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**How many people do you currently care for?**

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**Are you the main carer?**

---

---

---

**Do you live with the person you care for at the moment?**

Yes ☐  
Some of the time ☐  
No ☐

**When did you first start caring for someone with a mental illness? (If you can't remember exactly, a rough estimate will do.)**

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**How many hours did you spend looking after the person you care for last week? (If you can't remember exactly, a rough estimate will do.)**

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**What is the illness/condition of the person you care for?**

Dementia (e.g. Alzheimer's Disease) ☐  
Psychosis / schizophrenia ☐  
Bi-polar disorder / manic depression ☐  
Other mental health problem ☐  
(please specify below)

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***MANY THANKS FOR YOUR HELP.***

## Appendix 4: Carer Well-Being and Support Questionnaire-v2 (short, 49-item)

<b>For office use only</b>	
<b>Trial ref:</b> _____	<b>Date received</b> _____
<b>Ind ref:</b> _____	<b>Date entered</b> _____

### **Carer Well-Being & Support** Developing a questionnaire for carers of people with a mental health problem or dementia

**Before completing this questionnaire, please make sure you have read the enclosed Participant Information Sheet. When you return this questionnaire we will take it to mean that you have read the sheet and consent to take part in the project.**

Thank you for agreeing to help us improve this questionnaire. Before you start filling it in, there are a few things you should know.

- ❖ This questionnaire is for you as a carer to talk about your own circumstances and needs, and not those of the person you care for. We recognise that carers' needs are closely linked with the needs of the person they care for, but this questionnaire has been designed to find out about YOUR circumstances and YOUR needs.
- ❖ Please try to answer every question; there are no wrong or right answers.
- ❖ We recognise that some carers may be caring for more than one person. For each question, **choose one answer** that best reflects your caring responsibilities as a whole.
- ❖ The first section of the questionnaire asks about how you have been over the past 4 weeks. We recognise that this may have been an unusual time for you. However, we would like you to respond about your well-being in the last 4 weeks specifically. If you would like to tell why this has been an unusual time, there is space to do so at the end of the section.
- ❖ By completing the questionnaire and sending it back to us, you will help us to find out how well it works. We are not conducting a survey of carers.

Each questionnaire comes with a FREEPOST envelope so you can send it back when you've finished. If you don't have the envelope, you can still return it to us free of charge at the following address:

**Alan Quirk  
CUES-C (CWS) Development Project  
Royal College of Psychiatrists Research & Training Unit  
4<sup>th</sup> Floor, Standon House  
21 Mansell Street  
LONDON E1 8AA**

## A. Well-Being

The questions in Part A are about aspects of **your general well-being**. All of the questions are about how you have been over the past four weeks.

We recognise that some carers may be caring for more than one person. For each question, **tick one box on each line** that best reflects your caring responsibilities as a whole.

Please write **today's date**: \_\_\_\_\_

### Your role as a carer

The first set of questions asks about your **role as a carer**. (Please tick one box on each line.)

During the <u>past 4 weeks</u> , how concerned were you about...	A lot	Quite a bit	Moderately	A little	Not at all
1. not having enough time to yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. having to put the needs of the person you care for ahead of your own needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. not being able to take a break from caring?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. not being able to plan for the future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. not being able to continue caring due to reasons beyond your control (e.g. becoming ill yourself, looking after very young children)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Your relationship with the person you care for

The next questions are about your **relationship with the person you care for**. (Please tick one box on each line.)

During the <u>past 4 weeks</u> , how concerned were you about...	A lot	Quite a bit	Moderately	A little	Not at all
6. strains in your relationship with the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. the person you care for being too dependent on you <u>at the moment</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. the person you care for becoming too dependent on you <u>in the future</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. the person you care for saying things that upset you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. feeling irritable with the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. reaching 'breaking point', where you feel you can't carry on with things as they are?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3

### Your relationships with family and friends (Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
12. strains in your relationships with family and friends, because of your caring responsibilities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. "drifting apart" from family and friends, because your caring responsibilities limit the time available to keep in contact with them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. feeling isolated and lonely because of the situation you are in?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. not getting the support you need from family and friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Your financial situation (Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
16. your own financial situation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. the financial situation of the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. having to cover extra costs of caring (e.g. extra help in the home, trips to hospital)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Your physical health (Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
19. your own physical health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. your caring role making your physical health worse?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Your emotional well-being (Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
21. being unable to cope with the "constant anxiety" of caring?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. feeling depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. being unable to see anything positive in your life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. lack of sleep brought about through worry or stress?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. lack of sleep caused by the person you care for keeping you awake at night?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. feeling so exhausted that you can't function properly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4

## Stigma and discrimination

(Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
27. people treating you differently because of the illness/condition of the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your own safety

(Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about the person you care for...	A lot	Quite a bit	Moderately	A little	Not at all
28. accidentally doing something that puts you at risk (e.g. leaving the gas on)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. being aggressive or threatening towards you (e.g. verbal threats, sexual aggression, physical intimidation)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## The safety of the person you care for

(Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about the person you care for...	A lot	Quite a bit	Moderately	A little	Not at all
30. harming themselves?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. getting themselves into dangerous situations?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. relapsing or deteriorating, such that it puts their safety at risk?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

33. Overall, how would you rate your <b>general well-being</b> during the <u>past 4 weeks</u> ? (Please tick one box only.)	
Excellent	<input type="checkbox"/>
Very good	<input type="checkbox"/>
Good	<input type="checkbox"/>
Fair	<input type="checkbox"/>

## B. Support

The questions in Part B ask **how satisfied** you are, in general, with the **support you may receive** to help you in your role as a carer. Support may be provided by people working in the voluntary, private or statutory sectors, such as GPs, social workers, housing support workers, community psychiatric nurses, care workers, psychologists, psychiatrists, and carer support services or groups run by the voluntary sector.

Please tick the box on each line that best reflects your level of satisfaction with **the support you receive as a whole**.

### Information and advice for carers

The next questions ask about how satisfied you are with **information and advice** for carers. (Please tick one box on each line.)

<u>In general</u> , how satisfied are you...	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
1. that you have enough information about the condition/illness of the person you care for to enable you to feel confident in caring for them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. that you have enough information about how their condition/illness is likely to develop in the longer-term?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. that you can get whatever information you need when you need it (e.g. through your doctor or on your own)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. with how easy it is to understand the information you have?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. with the amount of advice available to you (e.g. from healthcare workers or other carers)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. that you are clear about who to go to for the information and advice you need?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. that you are clear about who to contact if there is an emergency and you need help right away?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. that you are clear about who to call if you have a routine inquiry?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Your involvement in treatment and care planning

(Please tick one box on each line.)

<u>In general</u> , how satisfied are you...	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
9. your involvement in important decisions (e.g. medication, hospitalisation)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. your ability to influence important decisions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6

## Support from medical and/or care staff

The following questions ask about **the support you may receive from medical and/or care staff** - that is, the people providing treatment and care for the person you care for (e.g. GPs, social workers, housing support workers, community psychiatric nurses, workers from the voluntary sector, psychologists and psychiatrists). (Please tick one box on each line.)

In general, how satisfied are you with...	Very satisfied	Somewhat satisfied	Somewhat Dissatisfied	Very dissatisfied
11. how easy it is to get help and support from staff for the <i>person you care for</i> (e.g. to prevent relapse)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. how easy it is to get help and support from staff for <i>yourself</i> (e.g. advice on how to deal with certain behaviours)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. the quality of help and support from staff for the <i>person you care for</i> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. your relationships with key staff who support the <i>person you care for</i> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. with how well the staff you have contact with are communicating with each other (i.e. that they share important information)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. with how seriously staff take what you say to them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. with the level of understanding staff have of what it must be like to be in your situation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

18. Overall, how satisfied are you with <b>the support you receive</b> to help you in your role as a carer? (Please tick one box only.)	
Very satisfied	<input type="checkbox"/>
Somewhat satisfied	<input type="checkbox"/>
Somewhat dissatisfied	<input type="checkbox"/>
Very dissatisfied	<input type="checkbox"/>

## C. Background Information

The following information will help us to understand your caring situation better and interpret your answers more effectively.

### About you

**1. Your date of birth?** \_\_\_\_\_

**2. Your gender?** Female ☐  
Male ☐

**3. Your ethnic background?**

*White:* British ☐  
Irish ☐  
Other White background ☐

please state \_\_\_\_\_

*Mixed:* White and Black Caribbean ☐  
White and Black African ☐  
White and Asian ☐  
Other Mixed background ☐

please state \_\_\_\_\_

*Asian or Asian British:*  
Indian ☐  
Pakistani ☐  
Bangladeshi ☐  
Other Asian background ☐

please state \_\_\_\_\_

*Black or Black British:*  
Caribbean ☐  
African ☐  
Other Black background ☐

please state \_\_\_\_\_

*Chinese or other ethnic group:*  
Chinese ☐  
Other ☐

please state \_\_\_\_\_

**4. Your environment (the area you live in)?**

Rural ☐  
Semi-urban ☐  
Urban ☐

**5. Your employment status?**

Employed full-time ☐  
Employed part-time ☐  
Self-employed ☐  
Unemployed ☐  
Retired ☐  
Student ☐  
Unable to work due to caring responsibilities ☐  
Unable to work due to ill-health /disability ☐  
Other (please specify) ☐

**6. In what year did you first start caring for someone with a mental health problem/dementia?** (If you don't remember the exact year, please give an estimate of the year you started caring.)

\_\_\_\_\_  
\_\_\_\_\_

**7. Last week, approximately how many hours did you spend looking after someone with a mental health problem/dementia?**

\_\_\_\_\_  
\_\_\_\_\_

**Was this:**

More hours than usual? ☐  
About the same number of hours as usual? ☐  
Fewer hours than usual? ☐

**8. How many people with a mental health problem/dementia do you currently care for?**

1 person ☐  
2 persons ☐  
3 + persons ☐

## About the Person or Persons You Care For

This next section asks about the person or persons you care for with a mental health problem or dementia. Please respond about the person you care for using the first column of boxes ('Person 1'). If you care for more than one person with a mental health problem or dementia, please tick relevant boxes in the other two columns (Persons 2 & 3). There is space at the end of the questionnaire if you would like to tell us about any further caring responsibilities you may have.

### 9. Who do you care for?

	Person 1	Person 2	Person 3
My <b>son/daughter</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My <b>partner/spouse</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My <b>brother/sister</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My <b>parent</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My <b>friend</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Other</b> (please specify below tick box)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	_____	_____	_____
	_____	_____	_____

### 10. What is their illness/condition?

	Person 1	Person 2	Person 3
Dementia (e.g. Alzheimer's Disease)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychosis/schizophrenia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bi-polar disorder/manic depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other mental health problem (please specify below tick box)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	_____	_____	_____
	_____	_____	_____

### 11. Do you live with them at the moment?

	Person 1	Person 2	Person 3
Yes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Some of the time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
↳ If no, where are they currently living?			
Own/rented accommodation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Supported accommodation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
With other family member/friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Care home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify below tick box)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	_____	_____	_____
	_____	_____	_____

**12. Which of the following statements best describes your role as a carer?**

	Person 1	Person 2	Person 3
I am the <b>only</b> caregiver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I <b>share</b> caring responsibilities with others, but <b>I</b> am the <b>main</b> caregiver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I <b>share</b> caring responsibilities with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I share caring responsibilities, but <b>some else</b> is the <b>main</b> caregiver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify below tick box)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	_____	_____	_____
	_____	_____	_____

**Taking a Break****13. Which of the following types of support, if any, do you use to allow you to take a break from caring?** (Tick more than one box if required.)

Friends/family providing temporary care	<input type="checkbox"/>	Other respite care (please specify below)	<input type="checkbox"/>
Paid carers coming into the home	<input type="checkbox"/>	_____	
Paid carers providing care away from the home (e.g. care home)	<input type="checkbox"/>	_____	
Supported activities out of the home, for the person you care for	<input type="checkbox"/>	I'm unable to take a break from caring	<input type="checkbox"/>
Supported breaks for you and the person you care for, away from the home	<input type="checkbox"/>	I do not need support to take a break from caring	<input type="checkbox"/>
		I do not need to take a break from caring	<input type="checkbox"/>

### **Other Comments and Feedback**

14. Please use the space below to write down any comments about the questionnaire itself (e.g. layout, ease of use, etc.) or whether there is anything we've missed in the questionnaire.

15. Also, please let us know if there is anything else that's important to your well-being or support, that you would like help with or that you'd like to change.

***MANY THANKS FOR YOUR HELP.***

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## Appendix 5: Questionnaire Pack (CWS-v2 + IEQ-EU + GHQ-12)

1

For office use only	
Trial ref: _____	Date received _____
Ind ref: _____	Date entered _____

# Questionnaire pack

## **Questionnaires for completion**

- 1. Carer Well-Being & Support**
- 2. Involvement Evaluation**
- 3. General Health**

When you have completed the questionnaire pack, please return it in the **freepost envelope enclosed**. If you don't have the envelope, you can still return it to us free of charge at the following address:

**CUES-C (CWS) Development Project  
Royal College of Psychiatrists  
Research and Training Unit  
4<sup>th</sup> Floor, Standon House  
21 Mansell Street  
LONDON  
E1 8AA**

# **Carer Well-Being & Support**

## **Developing a questionnaire for carers of people with a mental health problem or dementia**

**Before completing this questionnaire, please make sure you have read the enclosed Participant Information Sheet. When you return this questionnaire we will take it to mean that you have read the sheet and consent to take part in the project.**

Thank you for agreeing to help us improve this questionnaire. Before you start filling it in, there are a few things you should know.

- ❖ This questionnaire is for you as a carer to talk about your own circumstances and needs, and not those of the person you care for. We recognise that carers' needs are closely linked with the needs of the person they care for, but this questionnaire has been designed to find out about YOUR circumstances and YOUR needs.
- ❖ Please try to answer every question; there are no wrong or right answers.
- ❖ We recognise that some carers may be caring for more than one person. For each question, **choose one answer** that best reflects your caring responsibilities as a whole.
- ❖ The first section of the questionnaire asks about how you have been over the past 4 weeks. We recognise that this may have been an unusual time for you. However, we would like you to respond about your well-being in the last 4 weeks specifically. If you would like to tell why this has been an unusual time, there is space to do so at the end of the section.
- ❖ By completing the questionnaire and sending it back to us, you will help us to find out how well it works. We are not conducting a survey of carers.

**See Appendix C for a copy of the CWS-v2, which  
was reproduced at this point in the  
questionnaire pack**

## Involvement Evaluation Questionnaire

### Completing the questionnaire

The questionnaire is divided into sections, each representing a different aspect of caring. Each part is headed by a brief explanatory paragraph to lead you into the theme of the section.

Only **one answer** is possible for each question, unless otherwise indicated - **please tick accordingly**. In some cases, we will ask you to fill in a few personal details, such as your age.

It is quite possible that in some cases, a question will not be relevant to your particular circumstances. The questionnaire will clearly indicate, therefore, which questions you can ignore and at which point you should start again.

The consequences of your caring for someone who has mental health problems might have existed for several years already, but it is important to bear in mind that this questionnaire is mostly concerned with an analysis of the **current** situation. Most of the questions, therefore, cover your experiences during the **past four weeks**, whilst a few questions are about your more long-term experience. The questions themselves will make this clear.

All information will be treated confidentially, and you do not have to give your name if you do not wish to. If there are questions which you would prefer not to answer, we will, of course, respect your wishes - in this case, however, please write '**no answer**' next to the question.

Take your time to answer each question in turn and remember that what matters most of all is that your answers truly reflect your own personal experience.

### The following questions are about the encouragement and care you have given to your relative/friend during the past four weeks.

1. *How often during the past four weeks have you **encouraged** your relative/friend to take proper care of her/himself (e.g. washing, bathing, brushing teeth, dressing, combing hair etc.)?*  
 Never ☐      sometimes ☐      regularly ☐      often ☐      (almost) always ☐
2. *How often during the past four weeks have you **helped** your relative/friend take proper care of her/himself (e.g. washing, bathing, brushing teeth, dressing, combing hair etc.)?*  
 Never ☐      sometimes ☐      regularly ☐      often ☐      (almost) always ☐
3. *How often during the past four weeks have you **encouraged** your relative/friend to eat enough?*  
 Never ☐      sometimes ☐      regularly ☐      often ☐      (almost) always ☐
4. *How often during the past four weeks have you **encouraged** your relative/friend to undertake some kind of activity (e.g. go for a walk, have a chat, hobbies, household chores)?*  
 Never ☐      sometimes ☐      regularly ☐      often ☐      (almost) always ☐
5. *How often during the past four weeks have you **accompanied** your relative/friend on some kind of outside activity, because he/she did not dare to go alone?*  
 Never ☐      sometimes ☐      regularly ☐      often ☐      (almost) always ☐

6. *How often during the past four weeks have you **ensured** that your relative/friend has taken the required medicine?*
- Not relevant: relative/friend has no medicines [ ]
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
7. *How often during the past four weeks have you **guarded** your relative/friend from committing dangerous acts (i.e. setting something alight, leaving the gas on, forgetting to stub cigarettes out etc.)?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
8. *How often during the past four weeks have you **guarded** your relative/friend from self-inflicted harm (i.e. cutting her/himself, excessive medicine intake, burning, suicide attempt etc.)?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
9. *How often during the past four weeks have you **ensured** that your relative/friend received sufficient sleep?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
10. *How often during the past four weeks have you **guarded** your relative/friend from drinking too much alcohol?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
11. *How often during the past four weeks have you **guarded** your relative/friend from taking illegal drugs?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
12. *How often during the past four weeks have you carried out tasks normally done by your relative/friend (household chores, financial matters, shopping, cooking etc.)?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
13. *How often during the past four weeks have you **encouraged** your relative/friend to get up in the morning?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
14. *How often during the past four weeks has your relative/friend disturbed your sleep?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]

**The following questions are about how you have got on with your relative/friend in the past four weeks.**

- 15.** *How often during the past four weeks has the atmosphere been strained between you both, as a result of your relative/friend's behaviour?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
- 16.** *How often during the past four weeks has your relative/friend caused a quarrel?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
- 17.** *How often during the past four weeks have you been annoyed by your relative/ friend's behaviour?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
- 18.** *How often during the past four weeks have you heard from **others** that they have been annoyed by your relative/friend's behaviour?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
- 19.** *How often during the past four weeks have you felt threatened by your relative/ friend?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
- 20.** *How often during the past four weeks have you thought of moving out, as a result of your relative/friend's behaviour?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
- 21.** *How often during the past four weeks have you been able to pursue your own activities and interests (e.g. work, school, hobbies, sports, visits to family and friends)?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]

**The following questions are about the worries which may arise from your involvement with a relative/friend who has mental health problems.**

22. *How often during the past four weeks have you **worried** about your relative/friend's **safety**?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
23. *How often during the past four weeks have you **worried** about the kind of **help/treatment** your relative/friend is receiving?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
24. *How often during the past four weeks have you **worried** about your relative/friend's **general health**?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
25. *How often during the past four weeks have you **worried** about how your relative/ friend would manage financially if you were no longer able to help?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
26. *How often during the past four weeks have you **worried** about your relative/friend's **future**?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
27. *How often during the past four weeks have you **worried** about **your own future**?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
28. *To what extent have your relative/friend's mental health problems been a **burden** to you during the past four weeks?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
29. *Have you got used to your relative/friend having mental health problems?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
30. *How often have you felt able to cope with your relative/friend's mental health problems?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]
31. *Has your relationship with your relative/friend changed **since the onset** of the mental health problems?*
- Never [ ]      sometimes [ ]      regularly [ ]      often [ ]      (almost) always [ ]

**The following questions are about the financial cost to you and your household, as a result of your relative/friend's mental health problems.**

*Have you, during the past four weeks, had to incur extra **expenses on behalf of your relative/friend**?*

	<b>yes</b>	<b>no</b>
<b>32.</b> Professional help for your relative/friend	[ ]	[ ]
<b>33.</b> Damage caused by your relative/friend	[ ]	[ ]
<b>34.</b> Large expenditures incurred by your relative/friend	[ ]	[ ]
<b>35.</b> Relative/friend's travel expenses	[ ]	[ ]
<b>36.</b> Medicine for your relative/friend	[ ]	[ ]
<b>37.</b> Paying off debts incurred by your relative/friend	[ ]	[ ]
<b>38.</b> Other expenses (please indicate):		
.....		
.....		
<b>39.</b> <i>If you add up all the <b>extra expenses</b> which you have incurred on behalf of your relative/friend <b>during the past four weeks</b>, what is the estimated total figure?</i>		
less than £25	[ ]	
£25 - £50	[ ]	
£50 - £125	[ ]	
£125 - £250	[ ]	
more than £250	[ ]	

***Please turn over to complete the final questionnaire.***

## General Health Questionnaire – 12 item

Thinking about the **services you have received to support you in your role as a carer**, please answer the questions below. We are interested in your honest opinions, whether they are positive or negative. *Please answer all of the questions.*

*Have you recently:*

- |     |   |                           |                           |                               |                             |
|-----|---|---------------------------|---------------------------|-------------------------------|-----------------------------|
| 1.  | been able to concentrate on what you're doing?        | <i>better than usual</i>  | <i>same as usual</i>      | <i>less than usual</i>        | <i>much less than usual</i> |
| 2.  | lost much sleep over worry?                           | <i>not at all</i>         | <i>no more than usual</i> | <i>rather more than usual</i> | <i>much more than usual</i> |
| 3.  | felt that you are playing a useful part in things?    | <i>more so than usual</i> | <i>same as usual</i>      | <i>less so than usual</i>     | <i>much less than usual</i> |
| 4.  | felt capable of making decisions about things?        | <i>more so than usual</i> | <i>same as usual</i>      | <i>less so than usual</i>     | <i>much less capable</i>    |
| 5.  | felt constantly under strain?                         | <i>not at all</i>         | <i>no more than usual</i> | <i>rather more than usual</i> | <i>much more than usual</i> |
| 6.  | felt you couldn't overcome your difficulties?         | <i>not at all</i>         | <i>no more than usual</i> | <i>rather more than usual</i> | <i>much more than usual</i> |
| 7.  | been able to enjoy your normal day-to-day activities? | <i>more so than usual</i> | <i>same as usual</i>      | <i>less so than usual</i>     | <i>much less than usual</i> |
| 8.  | been able to face up to your problems?                | <i>more so than usual</i> | <i>same as usual</i>      | <i>less able than usual</i>   | <i>much less able</i>       |
| 9.  | been feeling unhappy or depressed?                    | <i>not at all</i>         | <i>no more than usual</i> | <i>rather more than usual</i> | <i>much more than usual</i> |
| 10. | been losing confidence in yourself?                   | <i>not at all</i>         | <i>no more than usual</i> | <i>rather more than usual</i> | <i>much more than usual</i> |
| 11. | been thinking of yourself as a worthless person?      | <i>not at all</i>         | <i>no more than usual</i> | <i>rather more than usual</i> | <i>much more than usual</i> |
| 12. | been feeling reasonably happy, all things considered? | <i>more so than usual</i> | <i>same as usual</i>      | <i>less so than usual</i>     | <i>much less than usual</i> |

**MANY THANKS FOR YOUR HELP.**

## Appendix 6: Carer Well-Being and Support Questionnaire-final (CWS-v2, revised with track changes)

Note: The version of the CWS tested in the final field trial was subsequently modified to create the final version (Appendix 7). Major changes include the addition of a new section (Section C – 'Your Needs') and the removal of instructions for participants in the field trial. The revisions are shown below using the track changes function.

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### Carer Well-Being & Support

#### A questionnaire for carers of people with a mental health problem or dementia

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Before you start filling this questionnaire in, there are a few things you should know.

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- ❖ This questionnaire is for you as a carer to talk about your own circumstances and needs, and not those of the person you care for. We recognise that carers' needs are closely linked with the needs of the person they care for, but this questionnaire has been designed to find out about YOUR circumstances and YOUR needs.

- ❖ It can be filled in by anyone who has a role in caring for someone with a mental health problem or dementia. You don't have to be a person's main carer or live at the same address as them.

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- ❖ Please try to answer every question; there are no wrong or right answers.
- ❖ We recognise that some carers may be caring for more than one person. For each question, **choose one answer** that best reflects your caring responsibilities as a whole.
- ❖ The first section of the questionnaire asks about how you have been over the past 4 weeks. We recognise that this may have been an unusual time for you. However, we would like you to respond about your well-being in the last 4 weeks specifically. If you would like to tell us why this has been an unusual time, there is space to do so at the end of the questionnaire.

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Deleted: &lt;#&gt; By completing the questionnaire and sending it back to us, you will help us to find out how well it works. We are not conducting a survey of carers.¶

Each questionnaire comes with a FREEPOST envelope so you can send it back when you've finished. If you don't have the envelope, you can still return it to us free of charge at the following address:¶

¶

¶

Alan Quirk¶  
 CUES-C (CWS)  
 Development Project¶  
 Royal College of  
 Psychiatrists Research &  
 Training Unit¶  
 4<sup>th</sup> Floor, Standon House¶  
 21 Mansell Street¶  
 LONDON E1 8AA¶

¶

¶

## A. Well-Being

The questions in Part A are about aspects of **your general well-being**. All of the questions are about how you have been over the past four weeks.

We recognise that some carers may be caring for more than one person. For each question, **tick one box on each line** that best reflects your caring responsibilities as a whole.

Please write **today's date**: \_\_\_\_\_

### Your role as a carer

The first set of questions asks about your **role as a carer**. (Please tick one box on each line.)

During the <u>past 4 weeks</u> , how concerned were you about...	A lot	Quite a bit	Moderately	A little	Not at all
1. not having enough time to yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. having to put the needs of the person you care for ahead of your own needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. not being able to take a break from caring?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. not being able to plan for the future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. not being able to continue caring due to reasons beyond your control (e.g. becoming ill yourself, looking after very young children)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Your relationship with the person you care for

The next questions are about your **relationship with the person you care for**. (Please tick one box on each line.)

During the <u>past 4 weeks</u> , how concerned were you about...	A lot	Quite a bit	Moderately	A little	Not at all
6. strains in your relationship with the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. the person you care for being too dependent on you <u>at the moment</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. the person you care for becoming too dependent on you <u>in the future</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. the person you care for saying things that upset you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. feeling irritable with the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. reaching 'breaking point', where you feel you can't carry on with things as they are?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

23. being unable to see anything positive in your life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. lack of sleep brought about through worry or stress?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. lack of sleep caused by the person you care for keeping you awake at night?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. feeling so exhausted that you can't function properly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3

### Your relationships with family and friends (Please tick one box on each line.)

During the <u>past 4 weeks</u> , how concerned were you about...	A lot	Quite a bit	Moderately	A little	Not at all
12. strains in your relationships with family and friends, because of your caring responsibilities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. "drifting apart" from family and friends, because your caring responsibilities limit the time available to keep in contact with them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. feeling isolated and lonely because of the situation you are in?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. not getting the support you need from family and friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Your financial situation (Please tick one box on each line.)

During the <u>past 4 weeks</u> , how concerned were you about...	A lot	Quite a bit	Moderately	A little	Not at all
16. your own financial situation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. the financial situation of the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. having to cover extra costs of caring (e.g. extra help in the home, trips to hospital)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Your physical health (Please tick one box on each line.)

During the <u>past 4 weeks</u> , how concerned were you about...	A lot	Quite a bit	Moderately	A little	Not at all
19. your own physical health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. your caring role making your physical health worse?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Your emotional well-being (Please tick one box on each line.)

During the <u>past 4 weeks</u> , how concerned were you about...	A lot	Quite a bit	Moderately	A little	Not at all
21. being unable to cope with the "constant anxiety" of caring?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. feeling depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. being unable to see anything positive in your life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. lack of sleep brought about through worry or stress?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. lack of sleep caused by the person you care for keeping you awake at night?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. feeling so exhausted that you can't function properly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## B. Support

The questions in Part B ask **how satisfied** you are, in general, with the **support you may receive** to help you in your role as a carer. Support may be provided by people working in the voluntary, private or statutory sectors, such as GPs, social workers, housing support workers, community psychiatric nurses, care workers, psychologists, psychiatrists, and carer support services or groups run by the voluntary sector.

Please tick the box on each line that best reflects your level of satisfaction with **the support you receive as a whole**.

### Information and advice for carers

The next questions ask about how satisfied you are with **information and advice** for carers. (Please tick one box on each line.)

In general, <b>how satisfied</b> are you...	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
1. that you have enough information about the condition/illness of the person you care for to enable you to feel confident in caring for them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. that you have enough information about how their condition/illness is likely to develop in the longer-term?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. that you can get whatever information you need when you need it (e.g. through your doctor or on your own)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. with how easy it is to understand the information you have?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. with the amount of advice available to you (e.g. from healthcare workers or other carers)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. that you are clear about who to go to for the information and advice you need?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. that you are clear about who to contact if there is an emergency and you need help right away?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. that you are clear about who to call if you have a routine inquiry?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Your involvement in treatment and care planning

(Please tick one box on each line.)

In general, <b>how satisfied</b> are you <u>with</u> ...	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
9. your involvement in important decisions (e.g. medication, hospitalisation)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. your ability to influence important decisions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6

## Support from medical and/or care staff

The following questions ask about **the support you may receive from medical and/or care staff** - that is, the people providing treatment and care for the person you care for (e.g. GPs, social workers, housing support workers, community psychiatric nurses, workers from the voluntary sector, psychologists and psychiatrists). (Please tick one box on each line.)

<u>In general</u> , how satisfied are you with...	Very satisfied	Somewhat satisfied	Somewhat Dissatisfied	Very dissatisfied
11. how easy it is to get help and support from staff for the <i>person you care for</i> (e.g. to prevent relapse)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. how easy it is to get help and support from staff for <i>yourself</i> (e.g. advice on how to deal with certain behaviours)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. the quality of help and support from staff for the <i>person you care for</i> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. your relationships with key staff who support the <i>person you care for</i> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. how well the staff you have contact with are communicating with each other (i.e. that they share important information)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. how seriously staff take what you say to them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. the level of understanding staff have of what it must be like to be in your situation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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Deleted: 18. Overall, how satisfied are you with **the support you receive** to help you in your role as a carer? (Please tick one box only.)

... [2]

## **C. Your Needs**

The questions in Part C are about **your needs for support** to help you in your role as a carer

### **1. Would you like more support to help you in your role as a carer?**

No, not at all      ☐

Yes, a little      ☐

Yes, a lot      ☐

### **2. What types of additional support would you most like to receive?**

### **3. Is there anything else that's important to your well-being that you'd like help with or would like to change?**

## About the Person or Persons You Care For

This next section asks about the person or ~~persons you care for with a mental health problem~~ or dementia. Please respond about the person you care for using the first column of boxes ('Person 1'). If you care for more than one person with a mental health problem or dementia, please tick relevant boxes in the other two columns (Persons 2 & 3). There is space at the end of the questionnaire if you would like to tell us about any further caring responsibilities you may have.

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### 9. Who do you care for?

	Person 1	Person 2	Person 3
My <b>son/daughter</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My <b>partner/spouse</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My <b>brother/sister</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My <b>parent</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My <b>friend</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Other</b> (please specify below tick box)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### 10. What is their illness/condition?

	Person 1	Person 2	Person 3
Dementia (e.g. Alzheimer's Disease)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychosis/schizophrenia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bi-polar disorder/manic depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other mental health problem (please specify below tick box)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### 11. Do you live with ~~each other~~ at the moment?

Deleted: them

	Person 1	Person 2	Person 3
Yes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Some of the time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
↳ If no, where are they currently living?			
Own/rented accommodation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Supported accommodation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
With other family member/friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Care home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify below tick box)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**12. Which of the following statements best describes your role as a carer at the moment?**

	Person 1	Person 2	Person 3
I am the <b>only</b> caregiver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I <b>share</b> caring responsibilities with others, but <b>I</b> am the <b>main</b> caregiver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I <b>share</b> caring responsibilities with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I share caring responsibilities, but <b>someone else</b> is the <b>main</b> caregiver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify below tick box)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	_____	_____	_____
	_____	_____	_____

### Taking a Break

**13. Which of the following types of support, if any, do you use to allow you to take a break from caring?** (Tick more than one box if required.)

Friends/family providing temporary care	<input type="checkbox"/>	Other respite care (please specify below)	<input type="checkbox"/>
Paid carers coming into the home	<input type="checkbox"/>	_____	
Paid carers providing care away from the home (e.g. care home)	<input type="checkbox"/>	_____	
Supported activities out of the home, for the person you care for	<input type="checkbox"/>	I'm unable to take a break from caring	<input type="checkbox"/>
Supported breaks for you and the person you care for, away from the home	<input type="checkbox"/>	I do not need support to take a break from caring	<input type="checkbox"/>
		I do not need to take a break from caring	<input type="checkbox"/>

---

## Appendix 7: Carer Well-Being and Support Questionnaire-final (CWS-v2)

### Carer Well-Being & Support

#### A questionnaire for carers of people with a mental health problem or dementia

Before you start filling this questionnaire in, there are a few things you should know.

- ❖ This questionnaire is for you as a carer to talk about your own circumstances and needs, and not those of the person you care for. We recognise that carers' needs are closely linked with the needs of the person they care for, but this questionnaire has been designed to find out about YOUR circumstances and YOUR needs.
- ❖ It can be filled in by anyone who has a role in caring for someone with a mental health problem or dementia. You don't have to be a person's main carer or live at the same address as them.
- ❖ Please try to answer every question; there are no wrong or right answers.
- ❖ We recognise that some carers may be caring for more than one person. For each question, **choose one answer** that best reflects your caring responsibilities as a whole.
- ❖ The first section of the questionnaire asks about how you have been over the past 4 weeks. We recognise that this may have been an unusual time for you. However, we would like you to respond about your well-being in the last 4 weeks specifically. If you would like to tell us why this has been an unusual time, there is space to do so at the end of the questionnaire.

## A. Well-Being

The questions in Part A are about aspects of **your general well-being**. All of the questions are about how you have been over the past four weeks.

We recognise that some carers may be caring for more than one person. For each question, **tick one box on each line** that best reflects your caring responsibilities as a whole.

Please write **today's date**: \_\_\_\_\_

### Your role as a carer

The first set of questions asks about your **role as a carer**. (Please tick one box on each line.)

During the <u>past 4 weeks</u> , how concerned were you about...	A lot	Quite a bit	Moderately	A little	Not at all
1. not having enough time to yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. having to put the needs of the person you care for ahead of your own needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. not being able to take a break from caring?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. not being able to plan for the future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. not being able to continue caring due to reasons beyond your control (e.g. becoming ill yourself, looking after very young children)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Your relationship with the person you care for

The next questions are about your **relationship with the person you care for**. (Please tick one box on each line.)

During the <u>past 4 weeks</u> , how concerned were you about...	A lot	Quite a bit	Moderately	A little	Not at all
6. strains in your relationship with the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. the person you care for being too dependent on you <u>at the moment</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. the person you care for becoming too dependent on you <u>in the future</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. the person you care for saying things that upset you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. feeling irritable with the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. reaching 'breaking point', where you feel you can't carry on with things as they are?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your relationships with family and friends (Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
12. strains in your relationships with family and friends, because of your caring responsibilities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. "drifting apart" from family and friends, because your caring responsibilities limit the time available to keep in contact with them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. feeling isolated and lonely because of the situation you are in?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. not getting the support you need from family and friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your financial situation (Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
16. your own financial situation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. the financial situation of the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. having to cover extra costs of caring (e.g. extra help in the home, trips to hospital)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your physical health (Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
19. your own physical health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. your caring role making your physical health worse?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your emotional well-being (Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
21. being unable to cope with the "constant anxiety" of caring?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. feeling depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. being unable to see anything positive in your life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. lack of sleep brought about through worry or stress?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. lack of sleep caused by the person you care for keeping you awake at night?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. feeling so exhausted that you can't function properly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Stigma and discrimination

(Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about...	A lot	Quite a bit	Moderately	A little	Not at all
27. people treating you differently because of the illness/condition of the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your own safety

(Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about the person you care for...	A lot	Quite a bit	Moderately	A little	Not at all
28. accidentally doing something that puts you at risk (e.g. leaving the gas on)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. being aggressive or threatening towards you (e.g. verbal threats, sexual aggression, physical intimidation)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## The safety of the person you care for

(Please tick one box on each line.)

During the <u>past 4 weeks</u> , <b>how concerned</b> were you about the person you care for...	A lot	Quite a bit	Moderately	A little	Not at all
30. harming themselves?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. getting themselves into dangerous situations?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. relapsing or deteriorating, such that it puts their safety at risk?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## B. Support

The questions in Part B ask **how satisfied** you are, in general, with the **support you may receive** to help you in your role as a carer. Support may be provided by people working in the voluntary, private or statutory sectors, such as GPs, social workers, housing support workers, community psychiatric nurses, care workers, psychologists, psychiatrists, and carer support services or groups run by the voluntary sector.

Please tick the box on each line that best reflects your level of satisfaction with **the support you receive as a whole**.

### Information and advice for carers

The next questions ask about how satisfied you are with **information and advice** for carers. (Please tick one box on each line.)

<u>In general</u> , how satisfied are you...	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
1. that you have enough information about the condition/illness of the person you care for to enable you to feel confident in caring for them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. that you have enough information about how their condition/illness is likely to develop in the longer-term?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. that you can get whatever information you need when you need it (e.g. through your doctor or on your own)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. with how easy it is to understand the information you have?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. with the amount of advice available to you (e.g. from healthcare workers or other carers)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. that you are clear about who to go to for the information and advice you need?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. that you are clear about who to contact if there is an emergency and you need help right away?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. that you are clear about who to call if you have a routine inquiry?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Your involvement in treatment and care planning

(Please tick one box on each line.)

<u>In general</u> , how satisfied are you with...	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
9. your involvement in important decisions (e.g. medication, hospitalisation)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. your ability to influence important decisions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Support from medical and/or care staff

The following questions ask about **the support you may receive from medical and/or care staff** - that is, the people providing treatment and care for the person you care for (e.g. GPs, social workers, housing support workers, community psychiatric nurses, workers from the voluntary sector, psychologists and psychiatrists). (Please tick one box on each line.)

In general, how satisfied are you with...	Very satisfied	Somewhat satisfied	Somewhat Dissatisfied	Very dissatisfied
11. how easy it is to get help and support from staff for the <i>person you care for</i> (e.g. to prevent relapse)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. how easy it is to get help and support from staff for <i>yourself</i> (e.g. advice on how to deal with certain behaviours)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. the quality of help and support from staff for the <i>person you care for</i> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. your relationships with key staff who support the <i>person you care for</i> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. how well the staff you have contact with are communicating with each other (i.e. that they share important information)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. how seriously staff take what you say to them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. the level of understanding staff have of what it must be like to be in your situation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## C. Your Needs

The questions in Part C are about **your needs for support** to help you in your role as a carer

### 1. Would you like more support to help you in your role as a carer?

No, not at all ☐

Yes, a little ☐

Yes, a lot ☐

### 2. What types of additional support would you most like to receive?

### 3. Is there anything else that's important to your well-being that you'd like help with or would like to change?

## D. Background Information

The following information will help us to understand your caring situation better and interpret your answers more effectively.

### About you

#### 1. Your date of birth? \_\_\_\_\_

2. Your gender? Female ☐  
Male ☐

#### 3. Your ethnic background?

- White: British ☐  
Irish ☐  
Other White background ☐

please state \_\_\_\_\_

- Mixed: White and Black Caribbean ☐  
White and Black African ☐  
White and Asian ☐  
Other Mixed background ☐

please state \_\_\_\_\_

#### Asian or Asian British:

- Indian ☐  
Pakistani ☐  
Bangladeshi ☐  
Other Asian background ☐

please state \_\_\_\_\_

#### Black or Black British:

- Caribbean ☐  
African ☐  
Other Black background ☐

please state \_\_\_\_\_

#### Chinese or other ethnic group:

- Chinese ☐  
Other ☐

please state \_\_\_\_\_

#### 4. Your environment (the area you live in)?

- Rural ☐  
Semi-urban ☐  
Urban ☐

#### 5. Your employment status?

- Employed full-time ☐  
Employed part-time ☐  
Self-employed ☐  
Unemployed ☐  
Retired ☐  
Student ☐  
Unable to work due to caring responsibilities ☐  
Unable to work due to ill-health /disability ☐  
Other (please specify) ☐

#### 6. In what year did you first start caring for someone with a mental health problem/dementia? (If you don't remember the exact year, please give an estimate of the year you started caring.)

\_\_\_\_\_

\_\_\_\_\_

#### 7. Please estimate as best you can how many hours you spent last week looking after someone with a mental health problem/dementia?

\_\_\_\_\_

\_\_\_\_\_

#### Was this:

- More hours than usual? ☐  
About the same number of hours as usual? ☐  
Fewer hours than usual? ☐

#### 8. How many people with a mental health problem/dementia do you currently care for?

- 1 person ☐  
2 persons ☐  
3 + persons ☐

## About the Person or Persons You Care For

This next section asks about the person or persons you care for with a mental health problem or dementia. Please respond about the person you care for using the first column of boxes ('Person 1'). If you care for more than one person with a mental health problem or dementia, please tick relevant boxes in the other two columns (Persons 2 & 3). There is space at the end of the questionnaire if you would like to tell us about any further caring responsibilities you may have.

### 9. Who do you care for?

	Person 1	Person 2	Person 3
My <b>son/daughter</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My <b>partner/spouse</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My <b>brother/sister</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My <b>parent</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My <b>friend</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Other</b> (please specify below tick box)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	_____	_____	_____
	_____	_____	_____

### 10. What is their illness/condition?

	Person 1	Person 2	Person 3
Dementia (e.g. Alzheimer's Disease)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychosis/schizophrenia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bi-polar disorder/manic depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other mental health problem (please specify below tick box)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	_____	_____	_____
	_____	_____	_____

### 11. Do you live with each other at the moment?

	Person 1	Person 2	Person 3
Yes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Some of the time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
↳ <b>If no, where are they currently living?</b>			
Own/rented accommodation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Supported accommodation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
With other family member/friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Care home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify below tick box)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	_____	_____	_____
	_____	_____	_____

**12. Which of the following statements best describes your role as a carer at the moment?**

	Person 1	Person 2	Person 3
I am the <b>only</b> caregiver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I <b>share</b> caring responsibilities with others, but <b>I</b> am the <b>main</b> caregiver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I <b>share</b> caring responsibilities with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I share caring responsibilities, but <b>someone else</b> is the <b>main</b> caregiver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify below tick box)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	_____	_____	_____
	_____	_____	_____

**Taking a Break****13. Which of the following types of support, if any, do you use to allow you to take a break from caring? (Tick more than one box if required.)**

Friends/family providing temporary care	<input type="checkbox"/>	Other respite care (please specify below)	<input type="checkbox"/>
Paid carers coming into the home	<input type="checkbox"/>	_____	
Paid carers providing care away from the home (e.g. care home)	<input type="checkbox"/>	_____	
Supported activities out of the home, for the person you care for	<input type="checkbox"/>	I'm unable to take a break from caring	<input type="checkbox"/>
Supported breaks for you and the person you care for, away from the home	<input type="checkbox"/>	I do not need support to take a break from caring	<input type="checkbox"/>
		I do not need to take a break from caring	<input type="checkbox"/>

---

## Appendix 8: Item Tracking Device – from CWS-v1 to CWS-v2

The item tracking device overleaf is essentially an audit trail of concepts and items on the CWS. It shows the point at which concepts and items in the long 74-item CWS-v1 emerged, and tracks whether each item performed well-enough in the item reduction analyses (4.3) to be retained in the short version of the questionnaire (the CWS-v2).

### **Point of emergence of concepts and items in long 74-item CWS-v1 (see columns 'CWS-v1 Concepts' & 'CWS-v1 items')**

The numbers in brackets beside each concept or item in the second and third columns denotes the stage of the 'deconstruction' process in/through which the concept or item emerged. (The deconstruction process is described in Chapter 3.)

- |   |  |
|---|--|
| 0 | Was in original CUES-C questionnaire (Appendix 1)      |
| 1 | Psychometric re-analyses of original CUES-C data (3.3) |
| 2 | Workshops with carers (3.4)                            |
| 3 | Redrafting by research team (3.5)                      |
| 4 | Consultation with carers (3.7)                         |
| 5 | Review by measurement experts (3.8)                    |
| 6 | Pilot testing with carers (3.9)                        |
| 7 | Finalisation of CWS-v1 (3.10)                          |

### **Reason for elimination of items (column 'CWS-v2' items)**

The following abbreviations in the 'CWS-v2 items' column denote which particular psychometric test resulted in the elimination of an item (see 4.3).

- |     |                  |
|-----|------------------|
| I-t | Item-totals <0.4 |
| R   | Redundancy >0.75 |
| M   | Missing >5%      |
| FA  | Factor Analysis  |

<b>CWS-v1 DOMAINS</b>	<b>CWSv-1 CONCEPTS</b>	<b>CWS-v1 ITEMS</b>	<b>CWS-v2 ITEMS</b>	<b>CWS-v2 DOMAINS</b>
Domain A1: Your day-to-day life	- Lack of autonomy (0)	1. Having enough time to yourself (2) 2. Having a life of your own (3) 3. Putting your own needs ahead of the person you care for (3)	1. Not having enough time to yourself? <b>*Item eliminated (R)*</b> 2. having to put the needs of the person you care for above your on needs?	Domain A1: Your role as a carer
Domain A2: Your relationship with the person your care for	- Strains in relationship (0) - Dependency (2) - Cruelty/hurtfulness (2) - Irritability (4)	4. Strains in your relationship with the person you care for (2) 5. The person you care for being too dependent on you <u>at the moment</u> (2) 6. The person you care for becoming too dependent on you <u>in the future</u> (3) 7. The person you care for saying things that upset you (2) 8. Feeling irritable with the person you care for (4) 9. Reaching 'breaking point', where you feel you can't carry on with things as they are (2)	6. strains in your relationship with the person you care for? 7. The person you care for being too dependent on you <u>at the moment</u> ? 8. The person you care for becoming too dependent on you <u>in the future</u> ? 9. The person you care for saying things that upset you? 10. Feeling irritable with the person you care for? 11. Reaching 'breaking point', where you feel you can't carry on with things as they are?	Domain A2: Your relationship with the person your care for
Domain A3: Your relationships with family and friends	- Strains in relationships (0) - Loss of relationships (2) - Social isolation (2) - Lack of support from friends and family (7)	10. Strains in your relationships with family and friends, because of your caring responsibilities (2) 11. 'Drifting apart' from family and friends because your caring responsibilities limit the time available to keep in contact with them? (2) 12. Feeling isolated and lonely because of the situation you're in (2) 13. Not getting the support you need from family and friends? (7)	12. Strains in your relationships with family and friends, because of your caring responsibilities? 13. 'Drifting apart' from family and friends because your caring responsibilities limit the time available to keep in contact with them? 14. Feeling isolated and lonely because of the situation you are in? 15. Not getting the support you need from family and friends?	Domain A3: Your relationships with family and friends
Domain A4: Your	- Own financial	14. Your own financial situation (3)	16. Your own financial situation?	Domain A4:

financial situation	situation (0) - Financial situation of person cared for (2) - Debt (4)	15. The financial situation of the person you care for (2)	17. The financial situation of the person you care for?	Your financial situation
		16. Having to cover extra costs of caring (2)	18. Having to cover extra costs of caring?	
		17. Having to cover own living costs (e.g. bills/rent/mortgage) (4)	*Item eliminated (FA)*	
		18. Getting into debt (4)	*Item eliminated (I-t)*	
Domain A5: Your physical health	- General physical health (0) - Association between caring role and physical health (2) - Lack of sleep (2)	19. Your own physical health (2)	19. Your own physical health?	Domain A5: Your physical health
		20. Problems with your own physical health making it difficult to properly look after the person you care for (2)	*Item eliminated (R)*	
		21. Your caring role making your physical health worse (2)	20. Your caring role making your physical health worse?	
Domain A6: Your emotional well-being	- Anxiety (0) - Depression (0) - Insomnia (2) - Feeling tired (2)	22. Being unable to cope with the 'constant anxiety' of caring(2)	21. Being unable to cope with the 'constant anxiety' of caring?	Domain A6: Your emotional well-being
		23. Feeling depressed (2)	22. Feeling depressed?	
		24. Being unable to see anything positive in your life (3)	23. Being unable to see anything positive in your life?	
		25. Lack of sleep brought about through worry or stress(3)	24. Lack of sleep brought about through worry or stress?	
		26. Lack of sleep caused by the person you care for keeping you awake at night (3)	25. Lack of sleep caused by the person you care for keeping you awake at night?	
		27. Feeling so exhausted that you can't think or function properly (2)	26. Feeling so exhausted that you can't think or function properly?	
Domain A7: Stigma and discrimination	- Differential treatment (0) - Non-disclosure (2)	28. People treating you differently because of the illness/condition of the person you care for (2)	27. People treating you differently because of the illness/condition of the person you care for?	Domain A7: Stigma and discrimination
		29. Having to keep the illness/condition of the person you care for secret because of how you think other people	*Item eliminated (R)*	

		might react (2)		
		30. Having to keep the illness/condition of the person secret because he or she doesn't want other people to know about it (6)	*Item eliminated (I-t)*	
		31. Not being able to tell people the real reasons for things (e.g. why you had to miss an appointment), because you don't want people to know about the illness/condition of the person you care for? (3)	*Item eliminated (I-t)*	
Domain A8: Your own safety	- Accidental harm (2) - Aggression/threats (2)	32. Accidentally doing something that puts you at risk (2) 33. Being aggressive or threatening towards you (e.g. verbal threats, sexual aggression, physical aggression) (2)	28. Accidentally doing something that puts you at risk? 29. Being aggressive or threatening towards you (e.g. verbal threats, sexual aggression, physical aggression)?	Domain A8: Your own safety
Domain A9: The safety of the person you care for	- Accidental harm (2) - Deliberate self-harm (2) - Avoidance of danger (2) - Coping with difficult situations (4) - Relapse (2)	34. Harming themselves accidentally (3) 35. Harming themselves deliberately (2) 36. Getting themselves into dangerous situations (2) 37. Being unable to cope with difficult situations (4) 38. Relapsing or deteriorating, such that it puts their safety at risk (2)	30. Harming themselves? *Item eliminated (I-t)* 31. Getting themselves into dangerous situations? *Item eliminated (I-t)* 32. Relapsing or deteriorating, such that it puts their safety at risk?	Domain A9: The safety of the person you care for
Domain A10: Your role as a carer [combining 'Your	- Lack of autonomy (over choice to care) (0) - Inability to care (2) - Inability to cope	39. Not being able to continue caring due to reasons beyond your control (2) 40. Feeling trapped in your role as a carer because there is no alternative to what you are currently doing (2)	5. Not being able to continue caring due to reasons beyond your control? *Item eliminated (R)*	Domain 1: Your role as a carer

ability and choice to care' and 'The demands of your role as a carer' (5)]	(2) - Dependency (2)	41. Not being able to plan things for the future (2)	4. Not being able to plan for the future?	
		42. Not being able to take a break (2) (4)	3. Not being able to take a break from caring?	
		43. Your caring role becoming too demanding (2)	*Item eliminated (R)*	

Domain B1: Information and advice for carers  [combining 'Availability of information and advice', 'Information about services for the person you care for' and Information about mental illness and its effects (5)]	- Availability of information and advice (0) - Availability of information about personnel (0) - Contact details (2) - Availability of information about mental illness and its effects (0) - Ease of understanding (2)	1. That you have enough information about the condition /illness of the person you care for to enable you to feel confident in caring for them (2)	1. That you have enough information about the condition /illness of the person you care for to enable you to feel confident in caring for them?	Domain B1: Information and advice for carers
		2. That you have enough information about how their condition/illness is likely to develop in the longer-term (3)	2. That you have enough information about how their condition/illness is likely to develop in the longer-term?	
		3. That you can get whatever information you need when you need it (7)	3. That you can get whatever information you need when you need it?	
		4. With how easy it is to understand the information you have (2)	4. With how easy it is to understand the information you have?	
		5. With the availability of information in your own language (3)	*Item eliminated (I-t)*	
		6. With the amount of advice available to you (3)	5. With the amount of advice available to you?	
		7. That you are clear about who to go to for the information & advice you need (4)	6. That you are clear about who to go to for the information & advice you need	
		8. That you are clear about who is, or who should be, providing treatment and care to the person you care for (2)	*Item eliminated (R)*	
		9. That you are clear about who to	7. That you are clear about who to	

		contact if there is an emergency and you need help right away (2)	contact if there is an emergency and you need help right away?	
		10. That you are clear about who to call if you have a routine enquiry (2)	8. That you are clear about who to call if you have a routine enquiry?	
Domain B2: Your involvement in treatment and care planning	- Involvement overall (0) - Involvement in decisions (2) - Influence on decisions (2)	11. Your involvement in important decisions (2)	9. Your involvement in important decisions?	Domain B2: Your involvement in treatment and care planning
		12. Your ability to influence important decisions (3)	10. Your ability to influence important decisions?	
Domain B3: Support from medical and/or care staff	- Frequency of contact (2) - Respect (2) - Empathy (2) - Trust (2) - Confidentiality (2) - Expressing complaints (2) - Amount of support (0) - Ease of access to support (2) - Quality of support (2)	13. How easy it is to get help & support from staff for the <i>person you care for</i> (2)	11. How easy it is to get help & support from staff for the <i>person you care for</i> ?	Domain B3: Support from medical and/or care staff
[Combining, 'Communication with care staff' and 'Support from care staff' (7)]		14. How easy it is to get help & support from care workers for <i>yourself</i> (2)	12. How easy it is to get help & support from care workers for <i>yourself</i> ?	
		15. The <i>amount</i> of help & support from staff for the <i>person you care for</i> (2)	*Item eliminated (R)*	
		16. The <i>quality</i> of the help & support from care workers to the <i>person you care for</i> (2)	13. The <i>quality</i> of the help & support from care workers to the <i>person you care for</i> ?	
		17. The <i>amount</i> of help & support from care workers for <i>yourself</i> (2)	*Item eliminated (R)*	
		18. The <i>quality</i> of the help & support from care workers for <i>yourself</i> (2)	*Item eliminated (R)*	
		19. Your relationships with key staff who support the person you care for (7)	14. Your relationships with key staff who support the person you care for?	
		20. That you are able to speak with care staff when you need to, either face to face or over the phone (3)	*Item eliminated (R)*	
		21. With how well the care staff you have contact with are communicating with each other (3)	15. With how well the care staff you have contact with are communicating with each other?	

		22. With how seriously staff take what you say to them (2)	16. With how seriously staff take what you say to them?	
		23. With the respect given to you by care staff (2)	*Item eliminated (R)*	
		24. With the level of understanding staff have of what it must be like to be in your situation (3)	17. With the level of understanding staff have of what it must be like to be in your situation	
		25. With the degree of trust you have in care staff to keep what you have told them private/confidential (2)	*Item eliminated (M)*	
		26. With your trust in staff to tell you everything you need to know (2)	*Item eliminated (M) (R)*	
		27. That you can openly express any complaints to staff (2)	*Item eliminated (R)*	
Domain B4: Support from other people	- Amount of support (2) - Quality of support (2)	28. The help and support from other people (2)	*Item eliminated (M)*	Domain B4: Support from other people
		Not applicable response category (7)	*Item eliminated (M)*	
Domain B5: Taking a break ('respite')	- Ease of access to respite care (2) - Quality of respite care (4) - Cost of respite care (4) - Guilt (2)	29. How easy it is for you to get respite care locally (2)	*Item eliminated (M)*	Domain B5: Taking a break ('respite')
		30. That good quality respite care is available if you want it (4)	*Item eliminated (M)*	
		31. With the cost of respite care (4)	*Item eliminated (M)*	
		Not applicable response category (7)		

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Covering letter – NHS recruitment, Final Field Test

[Date]

Dear

**Carer Well-Being & Support**

To provide effective support for carers, it is important that we find the best way of assessing carers' well-being and satisfaction with the services they receive. We are carrying out a research project to develop a new questionnaire to ensure that we understand the experiences of carers.

The project is being carried out by the Royal College of Psychiatrists, the mental health charity Rethink and The Alzheimer's Society. It is funded by the National Institute for Health Research, part of the Department of Health, and is being supported by [name of NHS Trust].

This questionnaire is the only one of its kind to be developed specifically for carers of people with a mental health problem or dementia, and is being developed with the active involvement of carers.

It is vital that the questionnaire covers the issues that carers think are important and provides an accurate picture of carers' experiences, so we would like you to help us by completing and returning the enclosed questionnaire pack. Your answers will help us to find out how well the new Carer Well-Being and Support questionnaire works in comparison with the other questionnaires in the pack.

Please read the Participant Information Sheet carefully as it describes the project in more detail.

We hope that you will be able to help us in developing this new questionnaire for carers. If you can return your completed questionnaire by [date] you will be entered into a **Prize Draw**. The winner will receive £75 in Marks & Spencers vouchers, with the two runners-up each receiving vouchers for £25.

Yours sincerely

Alan Quirk  
Research Fellow & Project Manager  
CUES-C (CWS) Development Project  
Tel. 020 7977 6648  
Email: aquirk@cru.rcpsych.ac.uk

19.09.07

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## Appendix 10: Participant Information Sheet (NHS Recruitment)

### Carer Well-Being & Support

#### **Participant Information Sheet**

We would like to invite you to take part in a research project to develop a questionnaire to evaluate i) the well-being of carers like you and ii) your satisfaction with the support you receive to help in your role as a carer. This sheet explains what the project is about and what we are asking you to do. Please take the time to read it before deciding whether to take part.

#### ***What is the project about?***

The aim of this project is to **develop a questionnaire** for carers for people with a mental health problem or dementia. The questionnaire aims to assess carers' *own* well-being and their satisfaction with the support they receive. When it is fully developed, the questionnaire will be used in a variety of ways, including helping carers to communicate with carer support staff about the support they need, and to evaluate the effectiveness of services for carers.

The questionnaire has been developed with the help and advice of carers. Now we need to find out how well it works.

#### ***Why have I been chosen?***

You have been chosen because you are currently on the caseload of a care co-ordinator in [name of Trust]. You have been randomly selected from the carers currently using these services.

#### ***What do you want me to do?***

If you would like to help with this project, **please fill in the enclosed questionnaire pack and send it back to us in the Freepost envelope provided.** The pack holds three questionnaires: the one we are developing (Carer Well-Being and Support), plus two others that measure similar things. The reason we ask for all of them to be filled in is that this will allow us to compare the performance of our questionnaire with others that are known to work well. This is not a survey and will not be used to assess you, or the services that you use. If we don't hear from you, we will send you a reminder letter in a couple of weeks' time.

**By returning the questionnaires, you are not promising to participate in any of the further stages of the project. We will not contact you again other than as described here. We will not pass your personal details on to any third party.**

The questionnaires do not have your name or address on them and the answers you give will not be linked to your personal details. The questionnaires have a unique number on them which will allow us to i) tell who has responded so that we don't send them a reminder letter, and ii) identify winners in the Prize Draw (see covering letter). At the end of the questionnaire there is a section which asks you for some background information

**P.T.O.**

about you and your caring situation. This will help us to interpret the results of the study. We will store all the returned questionnaires securely and they will be destroyed when the project has been completed.

At the end of the study, we will make the results available through your care co-ordinator and on the websites of Rethink, the Alzheimer's Society and the Royal College of Psychiatrists.

### ***Do I have to take part?***

It is up to you to decide whether you would like to take part. You should read this sheet carefully before deciding. Whether or not you choose to take part in this study will not affect the service you receive from the charities involved in the project.

### ***What are the benefits of taking part?***

By taking part in this project you will help us to develop a better way of assessing carers' needs. We hope this will benefit many carers by helping us to find the best way to meet those needs. You may also find that filling in the questionnaire now is helpful to you by making you think about your situation and what additional support you might need to help you as a carer.

### ***What are the risks of taking part?***

We do not think that involvement in this study will pose any risk to you, however some of the questions ask about personal and potentially stressful issues. If you find it difficult or upsetting to complete the questionnaire you can of course stop at any time or skip questions. If you feel you would like help or support due to any distress felt through completing this form, please contact the research team at the details below, or speak to your care co-ordinator, if you have one.

### ***Who can I contact for more information?***

If you would like further information on the project or would like to discuss it with someone from the research team at any stage, please contact:

Alan Quirk, email: [aquirk@cru.rcpsych.ac.uk](mailto:aquirk@cru.rcpsych.ac.uk), tel: 020 7977 6648

If you prefer, you may also discuss this with your care co-ordinator.

If you return the questionnaire we will take that to mean that you have read this sheet and consent to take part in the project.

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## Appendix 11: Consent Form (Training Course Recruitment)

Consent form – Training course recruitment, Final Field Test

### **Carer Well-Being & Support**

#### **Consent Form**

If you would like to take part in this research project, please initial each box and sign at the bottom to confirm the following:

1. I confirm that I have read and understand the information sheet dated 19.09.07 (version 1) for the CWS project. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my involvement in the training course or my legal rights being affected. ☐
3. I agree to take part in the above study. ☐

Your name \_\_\_\_\_

Date \_\_\_\_\_

Signature \_\_\_\_\_

**Please return this consent form along with your completed questionnaires in the Freepost envelope enclosed. This form will be separated from the anonymous questionnaires on receipt and stored securely.**

This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene & Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact [sdo@southampton.ac.uk](mailto:sdo@southampton.ac.uk).