Information needs of people with dementia and their carers
MSNAP Annual Forum 23 October 2013

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Reflective perspectives

“The Provider shall share relevant information with the patient and carer and help them to understand options and make informed choices in line with NICE/SCIE Clinical Guideline 42. However, the Provider shall be mindful of not overburdening the patient with information…”

(Memory service spec, DH)
Reflective perspectives: outline

1. Some of what we know about info needs
2. Alzheimer’s Society information portfolio
3. Perspectives about information – useful in developing our thinking
4. Illustration of perspectives by example
Info needs: selected literature

- The Information Challenge: Findings 2008
- Information needs of people with dementia and carers 2010
- The transition from cognitive impairment to dementia: older people’s experiences 2011
- Memory Services National Accreditation Programme (MSNAP) Standards for Memory Services 2012
Information needs: headlines 1

1. Info should be person-centred and user-led
2. Information topics:
Information needs: headlines 2

3. Information needs of person and family/carer overlap - but with some differences

4. Information needs clearly vary along ‘journey’ - and so with cognition

5. Strong preference still for print over web

6. Need for more for person with dementia, BAME groups, LD, sensory impairment

7. Biggest barrier to getting info: *I don’t know what I don’t know*
Alz Soc print information portfolio

Website also for:

- Podcasts
- Videos (YouTube)
- Shop
Quality standards

- **Accessible** – incl. writing, layout, design, format (health literacy)
- **Accurate** – evidencing, expertise, review
- **Appropriate**:
  - type of dementia
  - language
  - cultural references
  - imagery
Perspectives

DEMENTIA 'JOURNEY'

Diagnosis

Person

CONTEXT

LEVEL

National

Local

EoL

Family or carer (if any)

AUDIENCE
Illustrative examples

Memory handbook
A practical guide to living with memory problems

The dementia guide
Living well after a diagnosis

Advance decisions and advance statements

Making decisions and managing difficult situations

A diagnosis of dementia raises a range of practical and ethical issues, many requiring decisions to be made. At the point of the person with dementia progressing, some of those decisions will fall to a carer. This fact sheet offers guidance to carers on the relevant law (the Mental Capacity Act 2005). It then offers advice on how to approach decisions in a range of difficult areas.

As dementia progresses, the person’s cognitive (mental) abilities will decline, which will affect their ability to make their own decisions. When this happens, carers, family, and health and social care professionals will need to become more involved in helping the person make decisions. In some cases, others will have to make decisions for them.
Reflective perspectives: Summary

1. Please (continue to) reflect carefully about info needs and provision – part of person-centred care
   – Perspectives might provide a stimulus to thinking?

2. Alzheimer’s Society materials are information Standard accredited and will help you (continue to) meet MSNAP requirements
   – Please send feedback, thoughts or ideas
For more information

- Pick up a catalogue from me, **Tim Beanland**, or from **Andy Proctor** or **Gemma Jolly** at the Alzheimer’s Society stand over tea.

- Check out [www.alzheimers.org.uk/factsheets](http://www.alzheimers.org.uk/factsheets)
Berkshire Blue Book

• An approach to information provision
• Berkshire Healthcare Foundation Trust with Reading University
Berkshire Blue Book

- A resource for (patients) and carers through dementia journey
- Focus on information as part of the process of care
- Bringing together national information and local resources
- Information design and usability
I, for one, am the only person suffering from Terry Pratchett’s posterior cortical atrophy…

It is essential that support be provided bespoke to the individual and tailored to their needs…
Information needs and behaviours

User-centred design process

• Differing views through separate consultation of
  – family carers
  – multi-disciplinary memory clinic teams
  – GPs

• Iterative consultation during response development

• Before and after measures of family carers’ self-rating of
  – understanding of dementia
  – ability to cope
Information needs and behaviour

• Sarah and John

Siblings of Rachel (all in their 70s) who, after they cajoled her into seeing her GP, has been referred to a memory clinic and diagnosed with frontotemporal lobe dementia. Rachel lives alone, as she has always done, but Sarah and John are increasingly concerned for her safety as she is showing impaired judgement and ability to care for herself. Sarah and John both have spouses and wonder whether they could cope with taking turns to have Rachel stay with them.
Information needs *and* behaviour

- Richard

Richard suffered a minor stroke after elective surgery and, after scans to assess damage from the stroke, has been told he has vascular dementia. A doctor has told him he should contact the DVLA as, although he has recovered from the stroke, it may not be safe for him to continue to drive. He is furious. Having driven all his life he cannot imagine how he can manage without driving. He lives rurally and wonders what quality of life he can possibly have now.
Multiple perspectives at work

• Differences across
  – Dementia type
  – Stage of dementia (patient or carer information needs)
  – Who is caring – husband, wife, children (or no one)
  – Degree of insight of patient (and carer)

  – Almost invariably the need is, eventually, local
**How we are responding**

**Work in progress!**

<table>
<thead>
<tr>
<th>Introduction</th>
<th>Defining dementia</th>
<th>Everyday life</th>
<th>Financial and legal</th>
<th>Support</th>
<th>Record keeping</th>
</tr>
</thead>
</table>
| - About the handbook  
- Why you have been given the handbook?  
- How to use it | - Types of dementia  
- Range of symptoms  
- Intro of no dementia is the same, everybody progresses at different rates, symptoms can depend on what part of the brain is affected etc.  
- Effect on lifestyle and care  
- A–Z of symptoms  
  o Include tips i.e. Have you had your eyes tested recently?  
  o Who to contact  
  o Medication | - Family dynamics  
  o Ways for families to support each other  
  o Living alone/lack of family support  
  o Living at home vs residential care  
- Driving  
  o The issues & decision making  
  o Adaptations for  
    o **behaviour**  
    o **memory** loss  
    o **physical** complications  
  o tricks of the trade  
  - Keeping things simple  
  - Routine (trial & error)  
  - Stimulation of friends  
  - Best time of the day  
  - New memories | - Benefits and reliefs  
  o Funding  
  o Access to social care  
  o Help with applying  
  o Power of attorney  
  o Legal issues to consider and prepare for the future  
  - Consequences of legal issues not in place/alternative routes  
- Driving  
  o Legal: DVLA, insurance | - Who’s who – how services & roles link  
  o Which services are free, subsidised, payable & who to contact for more information  
- Local NHS services  
- Agencies  
- Charities  
- Triggers – decision tree of when it is advisable to action things  
  (nursing home, respite care, professional carers, charity support, aids in the home etc)  
- Where to go for more information  
  o How to make the most of the internet and information  
  o Support groups/activities within Berkshire (singing for the brain, thrive, AS café etc)  
  o Books  
  o Links  
  o Courses | - Carer course notes  
- Letters from hospital/GP  
- Appointment record  
- Notes/questions for next check-up  
- Medication details  
- Allergy record  
- Any other health issues to note  
- How to renew a prescription  
- Emergency contacts  
- GP name & contact  
- Dentist  
- Optician  
- Other relevant notes  
- 'This is me' / 'I have memory problems' card?  
- Remember to ask... |
Simplified structure

Introduction  Why you have been given this handbook

Defining dementia  Reminders: no dementia is the same
A–Z of symptoms

Everyday life  Practical and emotional adjustments
Home (or not), family and social connections)

Financial and legal  Putting plans in place
What you may be entitled to

Support  Medical and social support
Local agencies
Decision tree

Record keeping  Notes from carer courses
Letters and reminders
Issues this structure addresses

• Dispersed, sometimes inconsistent and often mislaid information
• Different conditions
• Limited time to consult, particularly web, information
• Need for
  – locally relevant as well as nationally available information
  – visible, shareable (with family members)
  – updatable
How do we know?

‘I couldn't follow up on all the things that are suggested … there are so many websites … and I just couldn't do it, basically I just didn't have the time to sit at the computer … because my husband is very very clinging … by the time he'd got to bed, I was so totally out that I just didn't have the energy to do anything’

‘We never get to see the psychiatrist. It’s always just a nurse’

‘Yes, yes, so when these things happen that you are totally unprepared for it, and you can make a note of it, I know a lot of things happen so you kind of forget, so you could jot that down’
Issues

• Duplication of information from other sources
• Confusing and worrying readers by presenting symptoms that may not be relevant for them
• Updating

But

• Outweighed by access to information after all diagnoses
• Regardless of individual patients’ decisions whether or not to engage with memory service

Your feedback would be very welcome
Would doctors routinely asking older patients about their memory improve dementia outcomes?

The UK government wants general practitioners to check for dementia in all patients aged 75 and older. Jill Rasmussen says that it will allow earlier support for patients with dementia, but Margaret McCartney says that industry has more to gain.

Most patients with dementia will live with the disease for years, and there is much that can be done to help them.

Earlier identification of dementia gives patients and their families more opportunity to consider the implications of the diagnosis and to make decisions while the patient can actively participate. Although no preventive or curative treatments are available, we have pharmacological interventions such as cholinesterase inhibitors that can optimise a patient’s capabilities during early dementia, enabling them to play more active roles in society, spend quality time with “near and dear”, and enjoy a better quality of life.

Many people attribute memory problems to old age. Unfortunately, many healthcare professionals are guilty of the same misconception when confronted with an older patient or concerned relative with memory complaints. Timely diagnosis in dementia gives the opportunity to maximise the benefits of current interventions.

Need for Better Care

The APPG report of Screening for Alzheimer’s Disease 2009 concluded that “an evidence-based routine screening programme for Alzheimer’s disease that will reduce mortality and morbidity is not yet available.”

We are already screening for dementia. Never mind the evidence-based conclusion from the UK National Screening Committee that “screening should not be offered,” our hospitals now receive financial incentives to do exactly that.

In early 2012 the Department of Health, now Commissioning for Quality and Innovation (CQUIN) payments aimed to increase the rate of diagnosis of Alzheimer’s disease by adding everybody admitted to hospital over the age of 75, whether they have been more forgetful in the past 12 months to the extent that it has significantly affected their daily life.”

The question has been or knowledge of the amount of harm that will be caused by over-investigation and the lack of consent for the process.

There are no known harms to patients at any stage of Alzheimer’s and, as the National Screening Committee noted, “the risks of over-investigation and over-treatment cannot be underestimated.”

The same document claims that anxiety will be raised unnecessarly, “only if the process is done badly,” and justifies by claiming that “doing nothing is not an option.”

Nevertheless, it allows that, “there will be no evidence-based screening, yet a growing acceptance that the NHS cannot offer adequate specialist care, and that people will be directed to the third sector instead.

Margaret McCartney

general practitioner, Glasgow, UK

margaret@margaretmccluney.com

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## MSNAP standards

### Support for People and their Carers

<table>
<thead>
<tr>
<th>3.8</th>
<th>The memory service is able to offer appropriate support, advice and information to people with memory problems/dementia and their carers at the time of assessment and diagnosis, as needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.8.1</td>
<td>People and their carers are given the opportunity to discuss what might come out of the assessment before it is carried out</td>
</tr>
<tr>
<td>3.8.2</td>
<td>Information is communicated sensitively</td>
</tr>
<tr>
<td>3.8.3</td>
<td>Information is communicated without unnecessary delay</td>
</tr>
<tr>
<td>3.8.4</td>
<td>When communicating important information to people, staff are able to dedicate adequate time</td>
</tr>
<tr>
<td>3.8.5</td>
<td>People are given adequate opportunities to talk through the implications of their diagnosis with members of the team, immediately after and/or during the days after receiving a diagnosis</td>
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</tbody>
</table>

**Guidance:** ascertain whether the supports offered were sufficient to meet the needs
### MSNAP standards

<table>
<thead>
<tr>
<th>3.8.7</th>
<th>The service routinely provides people and their carers with a variety of written information appropriate to their needs, about the following:</th>
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<tbody>
<tr>
<td>M</td>
<td>* Ref 15 – Pg 27-28, recommendation 1.4.6.2</td>
</tr>
<tr>
<td>3.8.7.1</td>
<td>• the signs and symptoms of dementia</td>
</tr>
<tr>
<td>3.8.7.2</td>
<td>• the course and prognosis of the condition</td>
</tr>
<tr>
<td>3.8.7.3</td>
<td>• options for care and treatment, including coping methods and strategies</td>
</tr>
<tr>
<td>3.8.7.4</td>
<td>• local care and support services/support groups</td>
</tr>
<tr>
<td>3.8.7.5</td>
<td>• sources of financial and legal advice, and advocacy</td>
</tr>
<tr>
<td>3.8.7.6</td>
<td>• medico-legal issues, including driving</td>
</tr>
<tr>
<td>3.8.7.7</td>
<td>• local and national information sources, including libraries, voluntary organisations and websites.</td>
</tr>
<tr>
<td>3.8.7.8</td>
<td>• improving general health, living positively and maximising quality of life after diagnosis</td>
</tr>
</tbody>
</table>

**Guidance:** This could include using mental exercise, physical activity, dietary advice alongside drug therapy, maintaining activities, lifestyle management and social engagement

<table>
<thead>
<tr>
<th>2 Ref 15</th>
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</thead>
</table>
Evidence


2008  Parker, D., Mills, S., & Abbey, J. Effectiveness of interventions that assist caregivers to support people with dementia living in the community: a systematic review. *International Journal of Evidence-Based Healthcare, 6*(2), 137-172.


2013  Abley, C., Manthorpe, J., Bond, J., Keady, J., Samsi, K., Campbell, S., ... & Robinson, L. Patients' and carers' views on communication and information provision when undergoing assessments in memory services. *Journal of health services research & policy, 18*(3), 167-173.
Positive contributors

Factors that appear to positively contribute to effective interventions:

• Involvement of person with dementia and caregiver
• Active participation in educational interventions for caregiver
• Individualised programs rather than group sessions
• Provide information on ongoing basis
• Target the care recipient particularly by reduction in behaviours

(Parker, 2008)
User contribution can help

Not so good…

Factors which do not appear to have benefit in interventions are those which:

- Simply refer caregivers to support groups
- Only provide self help materials
- Only offer peer support

(Parker, 2008)
PIF report 2013

Health literacy and health information producers
Report of the findings of a UK wide survey of information producers and providers

PIF: the UK association for consumer health information professionals

Alzheimer’s Society
Leading the fight against dementia

University of Reading | Centre for Information Design Research

Berkshire Healthcare NHS Foundation Trust
Providing first class services, to enable people to make the most of their lives
Does your organisation have any of the following in place to address the needs of people with low health literacy

<table>
<thead>
<tr>
<th>Service Type</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Audio/visual information designed for people with low health literacy</td>
<td>47 (24.9%)</td>
</tr>
<tr>
<td>Online/web based information designed for people with low health literacy</td>
<td>58 (30.7%)</td>
</tr>
<tr>
<td>Printed publications designed for people with low health literacy</td>
<td>84 (44.4%)</td>
</tr>
<tr>
<td>Telephone or face to face services</td>
<td>98 (51.9%)</td>
</tr>
<tr>
<td>User involvement or engagement with health literacy in mind</td>
<td>121 (64%)</td>
</tr>
<tr>
<td>A health literacy strategy or policy</td>
<td>18 (9.5%)</td>
</tr>
</tbody>
</table>

- Two thirds of respondents undertake user involvement with health literacy needs in mind.
- Half provide face to face and telephone information services; these are more likely to meet the needs of people with low health literacy.
- Fewer than 10% of respondents had a health literacy strategy or policy in place.
Summary

• ‘Information prescriptions’ are as important as medication
• Several benefits
  – reduced healthcare demands in primary and secondary care; – fewer hospital admissions
• More control and improved quality of life

SO….

SHOULD GOOD INFORMATION BE A STANDARD 1?
Thank you!

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• Dr Luke Solomons
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