

SAMPLE CHAPTER FROM:

# Schizophrenia

The NICE Guideline on Core Interventions in the Treatment and Management of Schizophrenia in Adults in Primary and Secondary Care

(Updated edition)

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## **2 SCHIZOPHRENIA**

This guideline is concerned with the treatment and management of what is called schizophrenia, and its related disorders. Although the precise terminology used for these disorders has been debated over the years, this updated guideline relates specifically to those identified by the tenth edition of the International Statistical Classification of Diseases and Related Health Problems (ICD–10; World Health Organization [WHO], 1992). These disorders are schizophrenia, schizoaffective disorder, schizophreniform disorder and delusional disorder. This updated guideline does not address the management of other psychotic disorders, such as bipolar disorder, mania or depressive psychosis, because they are covered by other guidelines.

### **2.1 THE DISORDER**

#### **2.1.1 Symptoms, presentation and patterns**

Schizophrenia is one of the terms used to describe a major psychiatric disorder (or cluster of disorders) that alters an individual's perception, thoughts, affect and behaviour. Individuals who develop schizophrenia will each have their own unique combination of symptoms and experiences, the precise pattern of which will be influenced by their particular circumstances.

Typically, the problems of schizophrenia are preceded by a 'prodromal' period. This is often characterised by some deterioration in personal functioning. Difficulties may include memory and concentration problems, social withdrawal, unusual and uncharacteristic behaviour, disturbed communication and affect, bizarre ideas and perceptual experiences, poor personal hygiene, and reduced interest in and motivation for day-to-day activities. During this prodromal period, people with schizophrenia often feel that their world has changed, but their interpretation of this change may not be shared by others. Relatives and friends frequently report that the person with schizophrenia has changed 'in themselves'. These changes may well affect the person's ability to hold down a job, study, or relate to family and friends.

The prodromal period is typically followed by an acute phase marked by characteristic positive symptoms of hallucinations, delusions, and behavioural disturbances, such as agitation and distress. Following resolution of the acute phase, usually because of some treatment, positive symptoms diminish or disappear for many people, sometimes leaving a number of negative symptoms not unlike the early prodromal period. This third phase, which may last many years, is often interrupted by acute exacerbations or 'relapses', which may need additional interventions.

Although this is a common pattern, the course of schizophrenia varies considerably. For example, although some people may experience disturbing symptoms only briefly, others may live with them for months or years. A number of individuals

experience no prodromal period, the disorder beginning with a sudden and often frightening acute episode. After an initial episode, between 14 and 20% of individuals will recover fully. Others will improve but have recurrences (see Section 2.1.3). Recurrence can be affected by stress, social adversity and isolation. In the longer term (up to 15 years), over half of those with these diagnoses will have episodic rather than continuous difficulties. As Harrow and colleagues (2005) have observed, 'some of these intervals of recovery will appear spontaneously and may be tied to individual patient factors, such as resilience'.

There is debate about the presentation of different symptoms and the prominence of affective symptoms among those diagnosed with schizophrenia from diverse cultural or ethnic backgrounds, and also over comorbidities and their prevalence across cultural and ethnic groups. There are few recent studies of such issues among populations in the UK, reflecting not only a serious omission but also that there may be reasons why people from specific ethnic backgrounds or socially excluded groups do not engage or benefit as much from services and treatments.

### **2.1.2 Impairment and disability**

Although the problems and experiences associated with schizophrenia are often distressing, the effects of the disorder can be pervasive. A significant number of people continue to experience long-term impairments, and as a result schizophrenia can have a considerable effect on people's personal, social and occupational lives. A European study of six countries found that over 80% of adults with this diagnosis had some persistent problems with social functioning, though not all of them were severe. The best predictor of poorer functioning in the long term was poor functioning in the first 3 years post-diagnosis (Wiersma *et al.*, 2000). Thornicroft and colleagues (2004) found that 80% remained unemployed.

The disabilities experienced by people with schizophrenia are not solely the result of recurrent episodes or continuing symptoms. Unpleasant side effects of treatment, social adversity and isolation, poverty and homelessness also play a part. These difficulties are not made any easier by the continuing prejudice, stigma and social exclusion associated with the diagnosis (Sartorius, 2002; Thornicroft, 2006).

Worldwide, it has been estimated that schizophrenia falls into the top ten medical disorders causing disability (WHO, 1990). Mortality among people with schizophrenia is approximately 50% above that of the general population, partly as a result of an increased incidence of suicide (about 10% die by suicide) and violent death, and partly as a result of an increased risk of a wide range of physical health problems. These include those illnesses associated with cigarette smoking, obesity and diabetes, as recent research has shown. The precise extent to which this excess mortality and high rates of disability are, at least in part, a result of some of the medications given for schizophrenia is still not clear. Difficulties experienced by mental health service users in accessing general medical services in both primary and secondary care continue to contribute to reduced life expectancy. Recent work indicates that young Caribbean and African men, and middle-aged women from diverse ethnic or cultural

backgrounds, are at higher risk of suicide, and that this may be because of differences in symptom presentation and conventional risk-factor profiles across ethnic groups (Bhui & McKenzie, 2008).

### **2.1.3 Prognosis, course and recovery**

Historically, many psychiatrists and other healthcare professionals have taken a pessimistic view of the prognosis for schizophrenia, regarding it as a severe, intractable and often deteriorating lifelong illness. This negative view has failed to find confirmation from long-term follow-up studies, which have demonstrated considerable variations in long-term outcome. While it is estimated that around three quarters of people with schizophrenia will experience recurrent relapse and some continued disability (Nadeem *et al.*, 2004), the findings of follow-up studies over periods of 20 to 40 years suggest that there is a moderately good long-term global outcome in over half of people with schizophrenia, with a smaller proportion having extended periods of remission of symptoms without further relapses (Gaebel & Fromman, 2000; Harrison *et al.*, 2001; Jobe & Harrow, 2005). It should also be noted that some people who never experience complete recovery from their experiences nonetheless manage to sustain an acceptable quality of life if given adequate support and help.

The early stages of schizophrenia are often characterised by repeated exacerbation of symptoms such as hallucinations and delusions and disturbed behaviour. While a high proportion respond to initial treatment with antipsychotic medication, around 80% will relapse within 5 years of a treated first episode, which is partly explained by discontinuation of medication (Nadeem *et al.*, 2004; Robinson *et al.*, 1999a, 2002). There is some evidence that early involvement in a progressive therapeutic programme incorporating social and psychological interventions as well as medication might be an important factor in realising long-term gains (de Haan *et al.*, 2003; Harrison *et al.*, 2001; Linszen *et al.*, 2001). Research has also suggested that delayed access to mental health services in early schizophrenia – often referred to as the duration of untreated psychosis – is associated with slower or less complete recovery, and increased risk of relapse and poorer outcome in subsequent years (Bottlender *et al.*, 2003; Harrigan *et al.*, 2003). In the longer term, the factors that influence the differential recovery from schizophrenia are not well known. But recovery may happen at any time, even after many years (Harrison *et al.*, 2001).

A number of social and economic factors also appear to affect the course of schizophrenia. For example, in developed countries it is well established that schizophrenia is more common in lower socioeconomic groups. However, this appears to be partly reversed in some developing countries (Jablensky *et al.*, 1992), suggesting that the relationship between incidence, recovery rates, and cultural and economic factors is more complex than a simple correspondence with socioeconomic deprivation (Warner, 1994).

The risk factors for developing schizophrenia and the acceptability of interventions and the uptake of treatments have been shown to vary across ethnic groups. Although the focus in the UK has been on African and Caribbean populations, early

evidence suggests other ethnic groups and migrants in general may be at risk; social risk factors may be expressed through an ethnic group, rather than being an intrinsic risk for that ethnic groups *per se*. However, the different pattern of service use, access to services and perceived benefits across ethnic groups is a cause of concern among service users.

The effects of schizophrenia on a person's life experience and opportunities are considerable; service users and carers need help and support to deal with their future and to cope with any changes that may happen.

#### **2.1.4 Diagnosis**

A full and proper discussion of the diagnosis and classification of schizophrenia is outside the scope of this updated guideline, although they are important issues in research and in clinical practice, and the impact of receiving a diagnosis of schizophrenia can have considerable social and personal consequences for the individual.

The wide variation in presentation, course and outcome in schizophrenia may reflect an underlying variation in the nature of the disorder, or even that schizophrenia is a cluster of different disorders with variable courses and outcomes (Gelder *et al.*, 1997). Equally, this variation may result from a complex interaction between biological, social, psychological, cultural and economic factors. Several models to explain this heterogeneity have been proposed, although none has been widely accepted. Moreover, prior to the establishment of diagnostic systems, such as the Diagnostic and Statistical Manual of Mental Disorders (DSM; American Psychiatric Association [APA], 1994) and the ICD (WHO, 1992), large variations in the incidence and prevalence of the disorder were reported. While DSM, ICD and similar systems have improved the reliability and consistency of diagnosis, considerable controversy exists as to whether a diagnosis of schizophrenia really represents a single underlying disorder.

Both ICD-10 and DSM-IV agree on the symptom clusters that confirm a diagnosis of schizophrenia. There are three main domains, including: psychotic symptoms, such as certain types of auditory hallucinations (hearing voices), delusions ('paranoia' and 'telepathy') and thought disorder (incomprehensible speech); negative symptoms, such as poor self-care, reduced motivation, reduced ability to experience pleasure, alogia (reduced production of thought), affective blunting (lack of emotional expression) and reduced social functioning; and the rarer symptom of catatonia. ICD-10 requires that at least one such diagnostic symptom from one of the three domains should be clearly present for 1 month. ICD-10 also confirms the diagnosis if two of these symptoms have been present in a less clear manner over the same time frame. The diagnosis is not made in the presence of prominent mood symptoms, such as depression or mania. In DSM-IV there is agreement with ICD-10 that diagnostic symptoms need to be present for at least 1 month. It also stipulates that there should be evidence of ongoing symptoms persisting for at least 6 months.

The uncertainty about diagnosis, and consequently its limited predictive validity, raises a number of important issues for service users. First, many clinicians in both primary and secondary care are reluctant to give this diagnosis, sometimes making it more difficult for people and their families to receive help early on. Second, some service users are reluctant to accept the diagnosis, and may reject suggestions that schizophrenia is an illness in need of treatment. Third, to receive a diagnosis of schizophrenia, with the stigma that this entails, seems to some a heavy price to pay given the diagnostic uncertainties that exist. Finally, some people diagnosed with schizophrenia object to receiving compulsory treatment for what they regard as no more than a putative illness.

That there are genuine problems with the diagnosis and classification of schizophrenia is not at question. However, for many people diagnosed with schizophrenia, the frequently painful and frightening experiences, and the disability often associated occur with or without the diagnosis. Moreover, to improve treatments and services for this group of people would be difficult without an operational diagnostic category with which to undertake research and the allocation of resources on the basis of proven need. Despite this practical requirement for diagnostic categories, caution is necessary to avoid making overly simplistic prognostications for individual service users. Professionals also have a duty to provide good, clear and honest information regarding schizophrenia, and about the treatments and services available.

### **2.1.5 Physical healthcare**

The association between schizophrenia and poor physical health is well established (Marder & Wirshing, 2003). Poor health results in higher standardised mortality rates and increased morbidity for individuals with schizophrenia (Saha *et al.*, 2008). It is apparent from epidemiological work that this excess morbidity and mortality is the result of a range of physical disorders, and not simply because of the effects of long-term antipsychotic medication or other factors, such as substance misuse, which are also associated with schizophrenia.

Reports on the mortality of people with schizophrenia indicate that there is an increased risk of death from circulatory conditions, infections and endocrine disorders. Despite high reported rates of smoking in people with schizophrenia, rates of lung cancer do not appear to be raised (Gulbinat *et al.*, 1992; Harris & Barraclough, 1998; Jeste *et al.*, 1996; Osborn *et al.*, 2007b). People with schizophrenia have higher rates of cardiovascular disease, including myocardial infarction, than the general population (Hennekens *et al.*, 2005; Lawrence *et al.*, 2003; Osborn *et al.*, 2007b).

Patients with schizophrenia are more likely than the general population to have lifestyle risk factors for cardiovascular disease and mortality (de Leon & Diaz, 2005; McCreadie *et al.*, 2003; Osborn *et al.*, 2006). They were found to be more likely to smoke even when the study population was controlled for socioeconomic status (Brown *et al.*, 1999; Osborn *et al.*, 2006). It has been suggested that high smoking rates in people with schizophrenia can be explained by the therapeutic effect of nicotine on psychotic symptoms and the reduction in side effects of

antipsychotic medication because of the enhanced metabolism of antipsychotic drugs in smokers (Jeste *et al.*, 1996). People with schizophrenia are also less likely to exercise and are more likely to have diets higher in fat and lower in fibre than the general population (Brown *et al.*, 1999; Osborn *et al.*, 2007a). People with schizophrenia are at increased risk of weight gain and this can be partly attributed to some of the newer antipsychotic drugs having a greater propensity to cause weight gain (American Diabetes Association *et al.*, 2004; Nasrallah, 2003, 2008). Recent evidence from a systematic review of trials on non-pharmacological treatments including individual or group interventions, cognitive behavioural therapy (CBT) and nutritional counselling indicated that these treatments were effective in reducing or attenuating antipsychotic-induced weight gain compared with treatment as usual (Álvarez-Jiménez *et al.*, 2008).

Antipsychotic medication may induce endocrine abnormalities (for example, diabetes and galactorrhoea), neurological disorders (for example, tardive dyskinesia), metabolic abnormalities (for example, lipid abnormalities and weight gain) and cardiovascular side effects (for example, lengthening of the QT interval on electrocardiography) (American Diabetes Association *et al.*, 2004; Dinan, 2004; Holt *et al.*, 2005; Koro *et al.*, 2002; Lieberman *et al.*, 2005; Lindenmayer *et al.*, 2003; Nasrallah, 2003, 2008; Saari *et al.*, 2004; Thakore, 2005).

The fact that this excess mortality and morbidity has a range of causes – including dietary and behavioural ones – suggests that lifestyle factors have a significant part to play. It could be that some of the problems associated with the development of schizophrenia impair or otherwise affect people's ability to manage their own physical health effectively. It is also likely that socioeconomic factors, including social exclusion, have a significant role to play. Nevertheless, there is also convincing evidence that psychiatrists and general practitioners (GPs) are poor at recognising and treating physical conditions, such as cardiovascular disorders in psychiatric patients (for a review see Osborn, 2001). A direct comparison of cardiovascular screening (that is, blood pressure, lipid levels and smoking status) of people with asthma, people with schizophrenia and other attendees indicated that GPs were less likely to screen people with schizophrenia for cardiovascular risk compared with the other two groups (Roberts *et al.*, 2007).

The development of case registers and specific remuneration of GPs for the monitoring of physical health problems for those with mental disorders, are contained within the new General Medical Services contract (Department of Health, 2003b), and has encouraged focus on these issues. The contract certainly provides opportunity for increased cooperation across the primary/secondary care interface, but as yet, the evidence for such interventions remains uncertain. Some early findings suggest that quite simple interventions might have some impact on the lifestyle factors associated with increased morbidity, for example group interventions for smoking cessation (Addington *et al.*, 1998). There is also evidence to suggest that people with schizophrenia are just as likely as others to attend their GP for cardiovascular screening as others without this diagnosis (Osborn *et al.*, 2003). Given this, careful consideration should be given to the role of GPs in the management of physical health problems. This is discussed further in Chapter 9 (Section 9.2).

## **2.2 INCIDENCE AND PREVALENCE**

Schizophrenia is a relatively common illness and it is certainly the most common form of psychotic disorder. The mean incidence of schizophrenia reported in epidemiological studies, when the diagnosis is limited to core criteria and corrected for age, is 0.11 per 1000 (range 0.07–0.17 per 1000); if broader criteria are used, this figure doubles to 0.24 per 1000 (range 0.07–0.52 per 1000) (Jablensky *et al.*, 1992). Average rates for men and women are similar, although the mean age of onset is about 5 years greater in women (hence a lower female rate in adolescence), with a second smaller peak after the menopause. The lifetime prevalence of schizophrenia is between 0.4 and 1.4% (Cannon & Jones, 1996). The National Survey of Psychiatric Morbidity in the UK found a population prevalence of probable psychotic disorder of 5 per 1000 in the age group 16 to 74 years (Singleton *et al.*, 2000).

## **2.3 POSSIBLE CAUSES OF SCHIZOPHRENIA**

The possible causes of schizophrenia are not well understood. Research has attempted to determine the causal role of biological, psychological and social factors. The evidence does not point to any single cause. Increasingly, it is thought that schizophrenia and related psychoses result instead from a complex interaction of multiple factors (Broome *et al.*, 2005; Garety *et al.*, 2007). Much of the research evidence on the aetiology of schizophrenia is consistent with the long-standing ‘vulnerability-stress’ model (Nuechterlein & Dawson, 1984). This paradigm suggests that individuals possess different levels of vulnerability to schizophrenia, which are determined by a combination of biological, social and psychological factors. It is proposed that vulnerability results in the development of problems only when environmental stressors are present. If there is great vulnerability, relatively low levels of stress might be sufficient to cause problems. If there is less vulnerability, problems develop only with higher levels of stress. The model is consistent with a wide variety of putative causes of the disorder, as well as the differential relapse and readmission rates observed among people with schizophrenia.

Recent research has therefore attempted to specify more precisely the nature of any vulnerability and of types of environmental stress. This includes biological hypotheses about brain biochemistry and pathology (Broome *et al.*, 2005), and attempts to identify genes that confer susceptibility (Craddock *et al.*, 2005). Biochemical theories have centred mainly on the ‘dopamine hypothesis’, for which there is enduring support (Kapur, 2003). This argues that schizophrenia might be related to problems in the regulation of the neurotransmitter dopamine in the prefrontal cortex.

Psychological factors can be divided into problems with basic cognitive functions, such as learning, attention, memory or planning, and biases in emotional and reasoning processes. Problems in cognitive function are related to research in brain structure and function, while emotional processes may be linked to social factors. Studies of psychological factors thus provide a bridge between biological and social theories.

Both types of psychological factor have been implicated in the development of symptoms of schizophrenia (Frith, 1992; Garety *et al.*, 2001, 2007; Gray *et al.*, 1991; Green, 1992; Hemsley 1993). Recently depression and anxiety, which were previously considered unimportant by researchers, have been found to contribute to the symptoms of schizophrenia (Birchwood, 2003; Freeman & Garety, 2003; Krabbendam & van Os, 2005).

Recently there has been a resurgence of interest in investigating social and environmental factors. Evidence has been accumulating to suggest that urban birth and rearing, social adversity and trauma, heavy cannabis use, migration and stressful life events all increase the risk of schizophrenia (Arseneault *et al.*, 2004; Bebbington *et al.*, 2004; Moore *et al.*, 2007; Read *et al.*, 2005; van Os *et al.*, 2005). There is now consistent evidence that migrant populations experience raised rates and especially high rates have been found among certain minority ethnic groups (Cantor-Graae & Selten, 2005; Kirkbride *et al.*, 2006). It is thought that this is most likely related to the high rates of social adversity and family disruption experienced by some migrant populations (Selten & Cantor-Graae, 2005; Fearon *et al.*, 2006).

## **2.4 ASSESSMENT**

Mental health assessments are conducted for a number of reasons: to reach a diagnosis, to develop a psychological formulation and identify strengths and needs, for screening purposes (including the detection of risk) and to measure outcomes. This guideline can only be implemented following a comprehensive biopsychosocial assessment. The assessment should provide an understanding of the presenting problems of the service user within the context of their life, both past and present, and should facilitate the development of a care plan that addresses a broad range of client needs beyond symptom reduction.

When comorbid conditions are identified, including substance misuse or physical illness, or if there is a forensic history, treatment and care plans that deal with these wider concerns will need to be developed, although these are outside the scope of this guideline.

Given the uncertainties surrounding the diagnosis of schizophrenia (see Section 2.1.4), it is important that following a full needs assessment, a comprehensive care plan is implemented whenever this diagnosis is suspected. Where a diagnosis has been reached, it should be fully explained and discussed with the service user (and with the carer where appropriate). The service user (and carer) may ask for a second opinion as many people are distressed about receiving the diagnosis and its potential implications.

## **2.5 ENGAGEMENT, CONSENT AND THERAPEUTIC ALLIANCE**

People with schizophrenia and its related disorders may be intensely distressed, especially during acute phases. This can manifest as fear, agitation, suspicion or

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anger. The development of a constructive therapeutic relationship is crucial to assessing accurately the nature of a person's problems and provides the foundation of any subsequent plan of management. Managing the process of engagement requires professionals to have sensitivity to the perspective of the individual and to understand that the condition can have a profound effect on the person's judgment, their capacity to understand their situation and their capacity to consent to specific interventions.

The process of engaging successfully with individuals with schizophrenia may at times require considerable persistence and flexibility from professionals. Establishment of trust is crucial and reliability and constancy on the part of professionals is an important component of this. The individual with schizophrenia may not share the professionals' view of what the main problem is. Seeking out and assisting with what the individual regards as the main problem can provide a route towards 'common ground'. This common ground can establish trust and collaboration, allowing further collaborative care planning over time.

All approaches must, of course, take place within a framework that acknowledges appropriate risk assessment. At times, individuals with schizophrenia may present sufficient risk to themselves or others to justify detention under the Mental Health Act (HMSO, 2007). Although the Mental Health Act will extend the powers of compulsory treatment, it is essential that any individual detained under the Act continues to be engaged as far as possible in a collaborative approach to their difficulties. Again, the constant seeking out of common ground and common objectives from consistent, reliable professionals is a vital part of this process. Individuals subject to the provisions of the Mental Health Act should be entitled to the highest quality of care from the most experienced and trained staff, including consultant psychiatrists.

Both the short- and long-term engagement of the individual is the foundation stone of any specific intervention including pharmacological interventions, psychosocial interventions and interventions aimed at addressing physical health. Favourably altering the medium- to long-term prognosis of the condition requires the development of broad-based, acceptable care plans developed in cooperation with the individual and, frequently, their relatives and carers. Continuity of care from professionals capable of communicating warmth, concern and empathy is important, and frequent changes of key personnel threaten to undermine this process. At the same time, having services available at short notice is at times important to ensure that urgent assessments can be provided in a timely and appropriate fashion. The NHS Plan (Department of Health, 2000) instituted the development of separate teams, such as crisis and home treatment teams, to try to address this. While such teams can offer a responsive service, they can at times struggle to maintain continuity of care. Other service changes have seen the development in some areas of separate teams for inpatients and community-based individuals. These service changes present further potential seams and discontinuities, which need to be actively managed to ensure adequate continuity of care. Assertive outreach teams and early intervention services, with their small caseloads and team-based approaches based around the individual, are well placed to manage this continuity, especially if the consultant psychiatrist to the team remains involved in any inpatient or crisis care.

Carers, relatives and friends of individuals with schizophrenia are important both in the process of assessment and engagement, and in the long-term successful delivery of effective interventions. Their views and needs must be acknowledged and should not be minimised or ignored.

Effective communication of care plans that follow a clear structure, are written in understandable language and preferably typed, provides a crucial contribution to the successful delivery of management strategies. This is particularly so in respect of providing clear guidance for emergency contacts and an outline of risks with associated contingency planning. This process should be managed in secondary services through the Care Programme Approach (CPA). Increasingly, the voluntary sector is providing a strong role in delivery and it is important that there is close working between these providers and the NHS services and that specific roles are clearly identified within care plans.

Issues of consent remain important throughout the care pathway. Professionals must be fully aware of all appropriate legislation, particularly the Mental Health Act (HMSO, 2007) and the Mental Capacity Act (HMSO, 2005). All reasonable steps need to be taken to engage individuals in meaningful discussion about issues relating to consent, and discussion with individuals should include specific work around relapse signatures, crisis plans, advance statements and advance decisions. The above statutory framework does provide for individuals with schizophrenia to make a contemporaneous decision to refuse treatment, though this could potentially be overruled by detention under the Mental Health Act.

## 2.6 LANGUAGE AND STIGMA

Although treatment for schizophrenia has improved since the 1950s and 1960s, some people with this diagnosis still encounter difficulties finding employment and may feel excluded from society. In an editorial for the *British Medical Journal*, Norman Sartorius claimed that 'stigma remains the main obstacle to a better life for the many hundreds of millions of people suffering from mental disorders' (Sartorius, 2002). In part because of media coverage of events associated with schizophrenia, people with the condition live with the stigma of an illness often seen as dangerous and best dealt with away from the rest of society. In this regard, research has shown that while the number of psychiatrically unrelated homicides rose between 1957 and 1995, homicides by people sent for psychiatric treatment did not, suggesting that the public fear of violence arising from people with schizophrenia is misplaced (Taylor & Gunn, 1999).

Those with schizophrenia may also feel stigmatised because of mental health legislation, including compulsory treatment in the community, which may exacerbate their feelings of exclusion. The side effects of the medication, such as hypersalivation, involuntary movements, sedation and severe weight gain, and the less than careful use of diagnostic labels, can all contribute to singling out people with schizophrenia, marking them as different. In addition, people with this condition may find that any physical health problems they have are not taken as seriously by health-care professionals.

In the view of many service users, clinical language is not always used in a helpful way, and may contribute to the stigma of schizophrenia. For example, calling someone a ‘schizophrenic’ or a ‘psychotic’ gives the impression that the person has been wholly taken over by an illness, such that no recognisable or civilised person remains. Many non-psychiatric health workers and many employers continue to approach people with schizophrenia in this way. There is a move away from using the word ‘schizophrenia’ for people with psychotic symptoms because the label is so unhelpful, especially in the early intervention services.

It is important that professionals are careful and considerate, but also clear and thorough in their use of clinical language and in the explanations they provide, not only to service users and carers but also to other healthcare professionals. Services should also ensure that all clinicians are skilled in working with people from diverse linguistic and ethnic backgrounds, and have a process by which they can assess cultural influences and address cumulative inequalities through their routine clinical practice (Bhui *et al.*, 2007). Addressing organisational aspects of cultural competence and capability is necessary alongside individual practice improvements.

Parents of people with schizophrenia often feel to blame, either because they have ‘passed on the genes’ causing schizophrenia, or because they are ‘bad parents’. However, the families of people with schizophrenia often play an essential part in the treatment and care of their relative, and with the right support and help can positively contribute to promoting recovery. The caring role can come at a high cost of depression and strain, and services need to remain sensitive to the separate needs of carers (see Section 2.7).

## **2.7 ISSUES FOR FAMILIES AND CARERS**

Carers, relatives and friends of people with schizophrenia are important both in the process of assessment and engagement in treatment and, in the long-term, successful delivery of effective interventions for people with schizophrenia. This guideline uses the term ‘carer’ to apply to all people who have regular close contact with the person, including advocates, friends or family members, although some family members may choose not to be carers.

As is explored in Chapter 4, carers have needs both in terms of providing support to the person with schizophrenia and requiring support for themselves. In their caring role, families and carers need detailed information about schizophrenia and many seek to be involved in some way in the person’s treatment and care, if the person consents. (The Royal College of Psychiatrists’ Partners in Care document on confidentiality contains useful guidance on the sharing of information; available from <http://www.rcpsych.ac.uk/PDF/Carersandconfidentiality.pdf>). But families and carers also need support for themselves, because they may be emotionally and psychologically affected by caring for someone with schizophrenia; they may be fearful, distressed and isolated, and these feelings can have a significant impact on their quality of life. As some personal accounts in Chapter 4 suggest, carers can feel neglected by health and social care services in terms of their own health and support needs and

become frustrated by the lack of opportunities to contribute to the development of the care plan for the person for whom they care.

## **2.8 TREATMENT AND MANAGEMENT OF SCHIZOPHRENIA IN THE NHS**

Until the 1950s, the treatment and management of schizophrenia generally took place in large asylums where people remained confined for much of their lives. Although government policy initiated a programme of gradual closure of these large hospitals and the rehousing of the residents in the community, this process was greatly assisted by the introduction of antipsychotic drugs, such as chlorpromazine, thioridazine and haloperidol. Antipsychotic medication would become the mainstay of treatment for the rest of the 20th century.

### **2.8.1 Pharmacological treatment**

Today, within both hospital and community settings, antipsychotic medicines remain the primary treatment for schizophrenia. There is well-established evidence for their efficacy in both the treatment of acute psychotic episodes and relapse prevention over time (Janicak *et al.*, 1993). However, despite this, considerable problems remain. A significant proportion of service users – up to 40% (Kane *et al.*, 1996; Klein & Davis, 1969) – have a poor response to conventional antipsychotic drugs and continue to show moderate to severe psychotic symptoms (both positive and negative).

In addition, conventional or typical antipsychotic agents (more recently called first-generation antipsychotics [FGAs]) are associated with a high incidence and broad range of side effects including lethargy, sedation, weight gain and sexual dysfunction. Movement disorders, such as parkinsonism, akathisia and dystonia (often referred to as acute extrapyramidal side effects [EPS]), are common and can be disabling and distressing. A serious long-term side effect is tardive dyskinesia, which develops in around 20% of people receiving FGAs (Kane *et al.*, 1985); this is a late-onset EPS characterised by abnormal involuntary movements of the lips, jaw, tongue and facial muscles, and sometimes the limbs and trunk. Although a person who develops tardive dyskinesia is usually unaware of the movements, they are clearly noticed by others, and the condition has long been recognised as a severe social handicap (Barnes & Kidger, 1978).

In response to the limited effectiveness and extensive side effects of FGAs, considerable effort has gone into developing pharmacological treatments for schizophrenia that are more effective and produce fewer or less disabling side effects. The main advantage of these second-generation ('atypical') antipsychotics (SGAs) appears to be that they have a lower liability for acute EPS and tardive dyskinesia. However, in practice this must be balanced against other side effects, such as weight gain and other metabolic problems that may increase the risk of type-2 diabetes and

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cardiovascular disease (American Diabetes Association *et al.*, 2004; Lindenmayer *et al.*, 2003; Mackin *et al.*, 2007; Nasrallah, 2003, 2008; Suvisaari *et al.*, 2007).

Raised serum prolactin is also an important adverse effect of antipsychotic medication, which can lead to problems such as menstrual abnormalities, galactorrhea and sexual dysfunction, and in the longer term to reduced bone mineral density (Haddad & Wieck, 2004, Meaney *et al.*, 2004).

In people with schizophrenia who have not responded well to other antipsychotics, only one antipsychotic drug, clozapine, has a specific license for the treatment of this group of people.

Further information about the antipsychotic medication reviewed for this update can be found in Chapters 6 and 7.

### **2.8.2 Psychological and psychosocial interventions**

The use of specific psychological and psychosocial methods to help people with schizophrenia is relatively recent. Some of the earliest attempts included psychoanalysis (Fromm-Reichman, 1950), and a modification of psychoanalysis designed to enhance better integration into a hospital environment (Stack-Sullivan, 1947). These pioneering efforts increased awareness of the psychological processes and personal impact of schizophrenia.

Since then, a number of other psychological approaches have been introduced. Social skills training, developed in the 1970s, was derived from the recognition of the social difficulties that many people with schizophrenia face, especially those in institutions, and used methods popular at the time based on learning theory and behaviourism (Shepherd, 1978). As deinstitutionalisation gained ground in the 1970s, psychological and social research into factors that might contribute to relapse in people living in community settings, such as stressful life events and communication difficulties in families (high expressed emotion), stimulated the development of family interventions to prevent relapse (Leff *et al.*, 1982). Family interventions often included education for family members about schizophrenia (sometimes called ‘psychoeducation’) and, in time, research was conducted on the benefits of psychoeducation alone.

By the late 1980s, CBT approaches, originally developed in the 1970s for depression, were first applied to aid the reduction of distressing psychotic symptoms and then broadened to work with emotional problems and functioning (Garety *et al.*, 2000). Another approach, cognitive remediation therapy (CRT), was also developed in the 1980s and 1990s, and differs from CBT in that it is not directed at distressing symptoms but is instead focused on training in cognitive functions, such as learning, planning, attention or memory (Green, 1993). A specific cognitive behavioural approach that aims to enhance compliance with medication was also developed towards the mid 1990s and is now commonly known as ‘adherence therapy’ (Kemp *et al.*, 1996).

Counselling and supportive psychotherapy, as well as various forms of group therapy and ‘milieu’ therapy, have long been practised with this client group. Finally,

the four arts therapies that emerged as organised professions in the middle of the last century have in recent years begun to be evaluated formally in trials (Crawford & Patterson, 2007).

The psychological approaches considered in this updated guideline are reviewed, with further description and definitions, in Chapter 8.

### **2.8.3 Service-level interventions**

Service-level interventions for people with schizophrenia include both ‘inpatient’ services and a variety of community team models. According to recent figures, services for people with schizophrenia account for 24% of the NHS spend on mental health (Mind, 2005). Two-thirds of that spend is on inpatient care where people with schizophrenia use over 60% of the provision (Knapp, 1997). The inpatient services comprise a range of statutory, independent and third sector provision ranging in degree of restriction and cost from high secure hospitals, medium secure and low secure units for mentally disordered offenders, through to intensive care, acute beds and rehabilitation units. The rates of use, care models and outcomes vary widely in these settings and there is no substantial evidence base for the optimal model, although a range of national regulators and peer review networks describe architectural ‘healing’ designs, standards and care pathways, for example, AIMS (Accreditation for Acute Inpatient Mental Health Services) initiated by the Royal College of Psychiatrists (2007) and the King’s Fund’s Enhancing the Healing Environment Programme (Waller & Finn, 2004).

Service-level interventions in the community include, most commonly, psychiatric outpatient clinics, generic locality community mental health teams (CMHTs), case management, acute day hospital care and non-acute day centre care. With the NSF policy directives and the various Mental Health Policy Implementation Guides being implemented in the past decade (for example, Department of Health, 1999; 2001), a growing number of crisis resolution and home treatment teams, assertive community treatment (ACT) or outreach teams and early intervention in psychosis services (EIPS) have been set up across the country. These new configurations in service delivery, though still evolving, have formed an increasingly important element in the management of all forms of severe mental illness, particularly psychoses. They emphasise an alternative to inpatient admission, with treatments and interventions focused on the service user’s usual environment and context.

Social interventions for people with schizophrenia should strive to promote recovery. As the National Institute for Mental Health in England (NIMHE) states: ‘Recovery is what people experience themselves as they become empowered to manage their lives in a manner that allows them to achieve a fulfilling, meaningful life and a contributing positive sense of belonging in their communities’ (NIMHE, 2005). An integrated social programme for supporting access to work, education and recreation is regarded as essential in addressing the impact on social function and isolation caused by schizophrenia. Social support and services looking at independent accommodation/housing, fighting stigma, improving access to meaningful

activities that address the individual's aspiration and strengths, and health promotion in the wider communities are all important considerations in realising the social inclusion principle (Repper & Perkins, 2003). Survey results amongst service users have also promoted the importance of social interventions that would improve/enhance more personal relationships, minimise discrimination, promote self-management, and ease social isolation through better availability of befriending and peer support schemes (Rethink, 2003).

#### **2.8.4 Primary–secondary care interface**

Most people with a diagnosis of schizophrenia in the care of the NHS are treated by secondary care mental health services. Surveys suggest that about 10 to 20% of service users are managed solely in primary care (Jeffreys *et al.*, 1997; Kendrick *et al.*, 2000; Rodgers *et al.*, 2003). This represents a significant shift from previous surveys (Johnstone *et al.*, 1984; Pantelis *et al.*, 1988) and may be an indication of the impact of recent changes in the structure and delivery of mental health services. This updated guideline therefore concentrates on the provision of care by secondary care services. It does not address the issue of the identification and initial diagnosis of schizophrenia, which is beyond its scope, although this is a key issue for primary care services.

Nevertheless, primary care services provide a vital service for people with schizophrenia, who consult primary care practitioners more frequently (Nazareth *et al.*, 1993) and are in contact with primary care services for a longer cumulative time than patients without mental health problems (Kai *et al.*, 2000; Lang *et al.*, 1997a, 1997b). A small percentage of service users have all their mental healthcare needs provided by primary care; this includes monitoring, treatment and support for their mental health problems in collaboration with secondary care services. Most receive much, if not all, of their physical care from primary care. Moreover, although most GPs regard themselves as involved in the monitoring and treatment of physical illness and prescribing for physical health problems, only a minority of GPs regard themselves as involved in the monitoring and treatment of mental health difficulties for people with schizophrenia (Bindman *et al.*, 1997; Burns *et al.*, 2000). Even fewer GPs are involved in secondary care CPA review meetings (Bindman *et al.*, 1997). Where possible, the guideline addresses these issues in its evidence-based recommendations. Where this is not possible, they are addressed through a number of good practice points, particularly in relation to the interface between primary and secondary care. Guidance on this interface has been incorporated into Chapter 9 on service interventions, with the aim of assisting primary care professionals in the management and referral of people with schizophrenia.

### **2.9 THE ECONOMIC COST OF SCHIZOPHRENIA**

Schizophrenia places a heavy burden on individuals and their carers, as well as potentially large demands on the healthcare system. In 1990, WHO ranked schizophrenia

as the ninth leading cause of disability among all diseases worldwide. When the burden of premature mortality and non-fatal health outcomes were combined and expressed in Disability Adjusted Life Years (DALYs), schizophrenia was the 26th leading cause of worldwide burden among all diseases and the ninth leading cause of DALYs at ages 15 to 44 years (Murray & Lopez, 1996).

A recent study estimated the total societal cost of schizophrenia at £6.7 billion (in 2004/2005 prices) only in England (Mangalore & Knapp, 2007). Of this, roughly £2 billion (about 30% of the total cost) comprised direct costs of treatment and care falling on the public purse, while the remaining £4.7 billion (70% of the total cost) constituted indirect costs to society. The cost of lost productivity of people with schizophrenia owing to unemployment, absence from work and premature mortality reached £3.4 billion, while the cost of lost productivity of carers was £32 million. The cost of informal care and private expenditures borne by families was reported to approximate £615 million. In addition, £1 million of the total cost was attributed to criminal justice system services, £570 million to benefit payments and another £14 million was associated with administration relating to these payments. Based on the above estimates, the average annual cost of a person with schizophrenia in England was calculated at approximately £55,000.

Davies and Drummond (1994) estimated that the lifetime total direct and indirect costs of a person with schizophrenia ranged from £8,000 (for a person with a single episode of schizophrenia) to £535,000 (for a person with multiple episodes lasting more than 2.5 years, requiring long-term care either in hospital or intensive community programmes) in 1990/1991 prices. Guest and Cookson (1999) estimated the average costs of a newly diagnosed person with schizophrenia at around £115,000 over the first 5 years following diagnosis, or approximately £23,000 annually (1997 prices). Of these, 49% were indirect costs owing to lost productivity.

Schizophrenia has been shown to place a substantial economic burden to the healthcare system and society worldwide: Wu and colleagues (2005) reported a total cost of schizophrenia in the US of US\$62.7 billion (2002 prices). More than 50% of this cost was attributed to productivity losses, caused by unemployment, reduced workplace productivity, premature mortality from suicide and family caregiving; another 36% was associated with direct healthcare service use and the remaining 12% was incurred by other non-healthcare services. In Canada, Goeree and colleagues (2005) estimated the total cost of schizophrenia at approximately CA\$2.02 billion (2002 prices). Again, productivity losses were by far the main component of this cost (70% of the total cost). In Australia, the total societal cost associated with schizophrenia reached AU\$1.44 billion in 1997/1998 prices, with roughly 60% relating to indirect costs (Carr *et al.*, 2003). Finally, several national studies conducted in Europe in the 1990s showed that schizophrenia was associated with significant and long-lasting health, social and financial implications, not only for people with schizophrenia but also for their families, other caregivers and the wider society (Knapp *et al.*, 2004b).

The use of hospital inpatient care by people with schizophrenia is substantial. In the financial year 2006–2007, 34,407 admissions were reported for schizophrenia and related disorders in England, resulting in 2,232,724 inpatient bed days. This amounted to 16% of all admissions and 34% of all bed days related to psychiatric

## *Schizophrenia*

inpatient care (NHS, The Information Centre, 2008A). Inpatient care is by far the most costly healthcare component in the overall treatment of schizophrenia. Kavanagh and colleagues (1995) found that care in short- or long-stay psychiatric hospitals accounted for 51% of the total public expenditure on care for people with schizophrenia. Lang and colleagues (1997a) reported that provision of inpatient care for people with schizophrenia amounted to 59% of the total cost of health and social care for this population. A more recent estimate suggested that inpatient care accounted for 56.5% of the total treatment and care costs of schizophrenia, compared with 2.5% for outpatient care and 14.7% for day care (Knapp *et al.*, 2002).

Unemployment is a considerable burden for people with schizophrenia. A recent review reported a rate of employment among people with schizophrenia of between 4 and 27% in the UK, with stigmatisation being one of the main barriers to employment for this population. The rates of employment were higher for newly diagnosed people compared with those with established schizophrenia; however, the majority of people presenting to services for the first time were already unemployed (Marwaha & Johnson, 2004). According to Guest and Cookson (1999), between 15 and 30% of people with schizophrenia are unable to work at diagnosis, rising to 67% following a second episode. Overall, the estimates of total indirect costs of people with schizophrenia in the UK range from £412 million for newly diagnosed people over the first 5 years following diagnosis (Guest & Cookson, 1999) to £1.7 billion annually for people with chronic schizophrenia (Davies & Drummond, 1994).

Family members and friends often provide care and support to those with schizophrenia, which places significant burdens on them that impact upon their health, leisure time, employment and financial status. Guest and Cookson (1999) estimated that, in the UK, 1.2 to 2.5% of carers gave up work to care for dependants with schizophrenia. Measuring the total cost of informal care provided by family members and friends is difficult but it is important to highlight that it is a significant amount. Data on costs of informal care for people with schizophrenia are not available. Based on figures provided by the Office for National Statistics (ONS), the Sainsbury Centre for Mental Health (2003) estimated that in 2002/2003 the aggregate value of informal care provided by family members and friends in the UK to those with mental health problems was £3.9 billion.

It is therefore evident that efficient use of available healthcare resources is required to maximise the health benefit for people with schizophrenia and, at the same time, reduce the emotional distress and financial implications to society.