

# **Psychosis and schizophrenia in children and young people: recognition and management**

## **NICE guideline**

**Draft for consultation, August 2012**

If you wish to comment on this version of the guideline, please be aware that all the supporting information and evidence is contained in the full version.

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## Introduction

Schizophrenia is a term used to describe a major psychiatric disorder (or cluster of disorders) that alters a person's perception, thoughts, affect and behaviour. The symptoms of schizophrenia are usually divided into 'positive symptoms' of psychosis, including hallucinations (perception in the absence of any stimulus) and delusions (fixed or falsely held beliefs), and 'negative symptoms' (such as emotional apathy, lack of drive, poverty of speech, social withdrawal and self-neglect). Children and young people who develop schizophrenia will have their own unique combination of symptoms and experiences, the precise pattern of which will be influenced by their circumstances and stage of development.

Schizophrenia is commonly preceded by a so-called prodromal period, lasting up to 12 months, in which the child or young person's behaviour and experience is altered. Relatives may become aware of this change before the person. Changes include the emergence of transient and/or attenuated psychotic symptoms, such as hallucinations and/or delusions. More subtly, the child or young person may become socially withdrawn or suspicious, with alterations in expressed feeling. Children and young people with such symptoms appear to be at higher risk than other children and young people of developing psychosis and schizophrenia up to 10 years after onset of symptoms.

Before a child or young person is diagnosed with schizophrenia, professionals usually recognise the presence of symptoms of psychosis and after assessment identify the type of psychosis, which may be schizophrenic or an affective (bipolar disorder or unipolar psychotic depression). This guideline applies to children and young people who have a psychosis before a diagnosis of schizophrenia, bipolar disorder or unipolar psychotic depression is made and also to those with a formal diagnosis of schizophrenia. The treatment and management of bipolar disorder and unipolar psychotic depression are covered by other NICE guidelines.

The prevalence of psychotic disorders in children aged between 5 and 18 years has been estimated to be 0.4% (the figure across all ages and populations in the UK is 0.7%). Schizophrenia accounts for 24.5% of all psychiatric admissions in young people aged 10–18 years (the overall admission rate is 0.46 per 1000 for this age range) with an exponential rise across the adolescent years. The rise in incidence increases most from age 15 onwards.

There is a worse prognosis for schizophrenia when onset is in childhood or adolescence. The symptoms and experience of schizophrenia are often distressing and the effects of the illness are pervasive. Although about one-fifth of children and young people with schizophrenia have a good outcome with only mild impairment, one-third have severe impairment that needs intensive social and psychiatric support. Schizophrenia can have a major detrimental effect on children and young people's personal, social, educational and occupational functioning, placing a heavy burden on them and their parents and carers.

Although the mainstay of treatment for all people with schizophrenia has been antipsychotic medication, there is limited evidence of its efficacy in children and young people. There are also concerns that children and young people are more sensitive than adults to the potential adverse effects of antipsychotics, including weight gain, metabolic effects and movement disorders. A number of psychological interventions, including family intervention, cognitive behavioural therapy (CBT) and arts therapies, have been used but, again, evidence is limited in children and young people and provision of these therapies for children and young people and for adults is variable.

This guideline covers the care provided by primary, community, secondary, tertiary and other health and social care professionals who have direct contact with, and make decisions concerning, the care of children and young people with psychosis or schizophrenia, including child and adolescent mental health services (CAMHS) and early intervention in psychosis services.

Early intervention in psychosis services provide people aged 15–35 years with a more intensive therapeutic service than traditional community services.

They are designed to intervene early, and deliver support and evidence-based interventions in a ‘normalising’ environment for the first 3 years after onset of psychosis.

There is considerable geographical variation in the configuration and integration of CAMHS and early intervention in psychosis services, and in the provision and integration of other services for children and young people with schizophrenia, including education, employment and rehabilitation, and social services. Provision for the needs of 16- and 17-year-olds with schizophrenia, in particular, can be fragmented and inadequate and they can experience difficulties in gaining access to appropriate accommodation and vocational or occupational support and rehabilitation.

A number of recommendations in this guideline have been adapted from recommendations in other NICE clinical guidelines. Where this occurred, the Guideline Development Group was careful to preserve the meaning and intent of the original recommendation. Changes to wording or structure were made in order to fit the recommendations into this guideline. In all cases, the original source of any adapted recommendation is indicated in a footnote.

The guideline incorporates NICE technology appraisal 213 (‘Aripiprazole for the treatment of schizophrenia in people aged 15 to 17 years’).

The guideline will assume that prescribers will use a drug’s summary of product characteristics (SPC) to inform decisions made with individual patients.

This guideline recommends some drugs for indications for which they do not have a UK marketing authorisation at the date of consultation, if there is good evidence to support that use. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council’s [Good practice in prescribing medicines – guidance for doctors](#) for further information. Where recommendations have been made for the use of Psychosis and schizophrenia in children and young people: NICE guideline

drugs outside their licensed indications ('off-label use'), these drugs are marked with a footnote in the recommendations.

## Person-centred care

This guideline offers best practice advice on the care of children and young people with psychosis or schizophrenia.

Treatment and care should take into account the child or young person's needs and preferences, and those of their parents or carers where appropriate. Children and young people with psychosis or schizophrenia should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals and their parents or carers. If the child or young person does not have the capacity to make decisions, healthcare professionals should follow the [Department of Health's advice on consent](#) and the [code of practice that accompanies the Mental Capacity Act](#). In Wales, healthcare professionals should follow [advice on consent from the Welsh Government](#).

If the child or young person is under 16, healthcare professionals should follow the guidelines in the Department of Health's '[Seeking consent: working with children](#)'.

Good communication between healthcare professionals, children and young people and their parents or carers is essential. It should be supported by evidence-based written information tailored to the child or young person's needs. Treatment and care, and the information children and young people and their parents or carers are given about it, should be culturally appropriate. It should also be accessible to children and young people with additional needs such as physical, sensory or learning disabilities, and to children and young people who do not speak or read English.

Parents and carers should be given the information and support they need. Other family members (such as siblings and grandparents) and significant others (such as valued friends) may be involved in the treatment and care of the child or young person and they also need information and support. Recommendations that include 'parents or carers' may also be relevant to them..

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Care of young people in transition between CAMHS and adult mental health services should be planned and managed according to the best practice guidance described in the Department of Health's ['Transition: getting it right for young people'](#).

CAMHS and adult mental health services should work jointly to provide assessment and services to children and young people with psychosis or schizophrenia. Diagnosis and management should be reviewed throughout the transition process, and there should be clarity about who is the lead clinician to ensure continuity of care.

## Key priorities for implementation

The following recommendations have been identified as priorities for implementation.

### Referral from primary care for possible psychosis

- When a child or young person experiences transient psychotic symptoms or other experiences suggestive of possible psychosis, refer for assessment without delay to a specialist mental health service such as CAMHS or an early intervention in psychosis service (14 years and over).

**[1.2.1]**

### Treatment options for symptoms not sufficient for a diagnosis of psychosis or schizophrenia

- When transient or attenuated psychotic symptoms or other mental state changes are not sufficient for a diagnosis of psychosis or schizophrenia, consider:
  - treatments recommended in NICE guidance for any recognised conditions such as anxiety, depression, emerging personality disorder or substance misuse, or
  - individual or family cognitive behavioural therapy (CBT) to decrease distress (delivered as set out in recommendation 1.3.27). **[1.2.5]**
- Do not offer antipsychotic medication for psychotic symptoms or mental state changes that are not sufficient for a diagnosis of psychosis or schizophrenia, or with the aim of decreasing the risk of psychosis. **[1.2.6]**

### Referral from primary care for first episode psychosis

- Urgently refer all children and young people with a first presentation of sustained psychotic symptoms (lasting 4 weeks or more) to a consultant psychiatrist with training in child and adolescent mental health in a specialist mental health service, either in CAMHS or an early intervention in psychosis service (14 years or over). **[1.3.1]**

### **Treatment options for first episode psychosis**

- If the child or young person and their parents or carers wish to try a psychological intervention alone (family intervention or individual CBT), inform them that there is little evidence that psychological interventions are effective without antipsychotic medication. Agree a time limit (1 month or less) for reviewing treatment options, including introducing antipsychotic medication. Continue to monitor symptoms, level of distress, impairment and level of functioning, including educational engagement and achievement, regularly. **[1.3.11]**

### **How to use oral antipsychotic medication<sup>1</sup>**

- Before starting antipsychotic medication, undertake and record the following baseline investigations:
  - weight and height (both plotted on a growth chart)
  - waist and hip circumference
  - pulse and blood pressure
  - fasting blood glucose, glycosylated haemoglobin (HbA<sub>1c</sub>), blood lipid profile and prolactin levels
  - assessment of any movement disorders
  - assessment of nutritional status, diet and level of physical activity. **[1.3.14]**
- Monitor and record the following regularly and systematically throughout treatment, but especially during titration:
  - efficacy, including changes in symptoms and behaviour
  - side effects of treatment, taking into account overlap between certain side effects and clinical features of schizophrenia (for example, the overlap between akathisia and agitation or anxiety)
  - the emergence of movement disorders

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<sup>1</sup> At the time of consultation (August 2012), most antipsychotic medication did not have a UK marketing authorisation specifically for children and young people. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Good practice in prescribing medicines – guidance for doctors](#) for further information.

- weight, weekly for the first 6 weeks, then at 12 weeks and then every 6 months thereafter (plotted on a growth chart)
- height every 6 months (plotted on a growth chart)
- waist and hip circumference every 6 months (plotted on a percentile chart)
- pulse and blood pressure (plotted on a percentile chart) at 12 weeks and then every 6 months thereafter
- fasting blood glucose, HbA<sub>1c</sub>, blood lipid and prolactin levels at 12 weeks and then every 6 months thereafter
- adherence
- physical health.

The secondary care team should maintain responsibility for physical monitoring of antipsychotic medication for at least the first 12 months or until the child or young person's condition has stabilised. Thereafter, the responsibility for physical monitoring may be transferred to primary care under shared care arrangements.

**[1.3.17]**

**Treatment of subsequent acute episodes of psychosis or schizophrenia**

- Offer family intervention to all families of children and young people with psychosis or schizophrenia, particularly for preventing and reducing relapse. This can be started either during the acute phase or later, including in inpatient settings. **[1.4.4]**
- Before referral for hospital care, think about the impact on the child or young person and their parents, carers and other family members, especially when the inpatient unit is a long way from where they live. Consider alternative care within the community wherever possible. If hospital admission is unavoidable, provide support for parents or carers when the child or young person is admitted. **[1.4.17]**

**Education, employment and occupational activities**

- For children and young people of compulsory school age, liaise with the child or young person's school and educational authority to ensure that ongoing education is provided. **[1.6.18]**



1.1.4 Health and social care providers should ensure that children and young people with psychosis or schizophrenia:

- can routinely receive care and treatment from a single multidisciplinary community team
- are not passed from one team to another unnecessarily
- do not undergo multiple assessments unnecessarily.<sup>5</sup>

1.1.5 Help the child or young person to continue their education. Contact the school or college, subject to consent, to ask for additional educational support if their performance has been affected by their condition.

### **Establishing relationships with children and young people and their parents or carers**

1.1.6 Work in partnership with children and young people with psychosis or schizophrenia and their parents or carers. Offer help, treatment and care in an atmosphere of hope and optimism. Take time to build trusting, supportive, empathic and non-judgemental relationships as an essential part of care.<sup>6</sup>

1.1.7 When working with children and young people with psychosis or schizophrenia of an appropriate developmental level, emotional maturity and cognitive capacity:

- aim to foster their autonomy, promote active participation in treatment decisions, and support self-management and access to peer support
- maintain continuity of individual therapeutic relationships wherever possible
- offer access to a trained advocate.<sup>7</sup>

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<sup>5</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

<sup>6</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

<sup>7</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

- 1.1.8 When working with children and young people with psychosis or schizophrenia and their parents or carers:
- make sure that discussions take place in settings in which confidentiality, privacy and dignity are respected
  - be clear with the child or young person and their parents or carers about limits of confidentiality (that is, which health and social care professionals have access to information about their diagnosis and its treatment and in what circumstances this may be shared with others).<sup>8</sup>
- 1.1.9 Discuss with young people with psychosis or schizophrenia of an appropriate developmental level, emotional maturity and cognitive capacity how they want their parents or carers to be involved in their care. Such discussions should take place at intervals to take account of any changes in circumstances, including developmental level, and should not happen only once.<sup>9</sup>
- 1.1.10 Advise parents and carers about their right to a formal carer's assessment of their own physical and mental health needs, and explain how to access this.<sup>10</sup>

### **Communication and information**

- 1.1.11 Health and social care professionals working with children and young people with psychosis or schizophrenia should be trained and skilled in:
- negotiating and working with parents and carers, and
  - managing issues relating to information sharing and confidentiality as these apply to children and young people.

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<sup>8</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

<sup>9</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

<sup>10</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

When a young person is 'Gillick competent' ask them what information can be shared before speaking to their parents or carers.

1.1.12 When communicating with children and young people with psychosis or schizophrenia and their parents or carers:

- take into account the child or young person's developmental level, emotional maturity and cognitive capacity including any learning disabilities, sight or hearing problems or delays in language development
- use plain language where possible and clearly explain any clinical language
- check that the child or young person and their parents or carers understand what is being said
- use communication aids (such as pictures, symbols, large print, Braille, different languages or sign language) if needed.

1.1.13 Provide children and young people with psychosis or schizophrenia and their parents or carers, comprehensive written information about:

- the nature of, and interventions for, psychosis and schizophrenia (including biomedical and psychosocial perspectives on causes and treatment) in an appropriate language or format, including any relevant 'Understanding NICE guidance' booklets
- support groups, such as third sector, including voluntary, organisations.<sup>11</sup>

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<sup>11</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).  
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1.1.14 Ensure that you are:

- familiar with local and national sources (organisations and websites) of information and/or support for children and young people with psychosis or schizophrenia and their parents or carers
- able to discuss and advise how to access these resources
- able to discuss and actively support children and young people and their parents or carers to engage with these resources.<sup>12</sup>

1.1.15 When communicating with a child or young person with psychosis or schizophrenia, use diverse media, including letters, phone calls, emails or text messages, according to their preference.<sup>13</sup>

1.1.16 Copy all written communications with other health or social care professionals to the child or young person and/or their parents or carers at the address of their choice, unless this is declined.<sup>14</sup>

### **Culture, ethnicity and social inclusion**

The following recommendations apply to all children and young people with psychosis or schizophrenia and their parents or carers. However, children and young people from black and minority ethnic (BME) groups with psychosis or schizophrenia are more likely than people from other groups to be disadvantaged or to have impaired access and/or engagement with mental health services. Their particular needs may be addressed by the following recommendations.

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<sup>12</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

<sup>13</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

<sup>14</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

- 1.1.17 When working with children and young people with psychosis or schizophrenia and their parents or carers:
- take into account that stigma and discrimination are often associated with using mental health services
  - be respectful of and sensitive to children and young peoples' gender, sexual orientation, socioeconomic status, age, background (including cultural, ethnic and religious background) and any disability
  - be aware of possible variations in the presentation of mental health problems in children and young people of different genders, ages, cultural, ethnic, religious or other diverse backgrounds.<sup>15</sup>
- 1.1.18 When working with children and young people with psychosis or schizophrenia and their parents or carers:
- provide and work proficiently with interpreters if needed
  - offer a list of local education providers who can provide English language teaching for children and young people and their parents or carers who have difficulties speaking and understanding English.
- 1.1.19 Health and social care professionals working with children and young people with psychosis or schizophrenia and their parents or carers should have competence in:
- assessment skills for people from diverse ethnic and cultural backgrounds
  - using explanatory models of illness for people from diverse ethnic and cultural backgrounds
  - explaining the possible causes of psychosis and schizophrenia and treatment options

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<sup>15</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).  
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- addressing cultural and ethnic differences in treatment expectations and adherence
- addressing cultural and ethnic differences in beliefs regarding biological, social and family influences on the possible causes of mental health problems
- conflict management and conflict resolution.<sup>16</sup>

1.1.20 Health and social care professionals inexperienced in working with children and young people with psychosis or schizophrenia from diverse ethnic and cultural backgrounds, and their parents or carers, should seek advice and supervision from healthcare professionals who are experienced in working transculturally.<sup>17</sup>

1.1.21 Local mental health services should work with primary care, other secondary care and local third sector, including voluntary, organisations to ensure that:

- all children and young people with psychosis or schizophrenia have equal access to services based on clinical need and irrespective of gender, sexual orientation, socioeconomic status, age, background (including cultural, ethnic and religious background) and any disability
- services are culturally appropriate.<sup>18</sup>

1.1.22 Mental health services should work with local voluntary black and minority ethnic groups to jointly ensure that culturally appropriate psychological and psychosocial treatment, consistent with this guideline and delivered by competent practitioners, is provided to children and young people from diverse ethnic and cultural backgrounds.<sup>19</sup>

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<sup>16</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>17</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>18</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

<sup>19</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

## **Transfer and discharge**

1.1.23 Anticipate that withdrawal and ending of treatments or services, and transition from one service to another, may evoke strong emotions and reactions in children and young people with psychosis or schizophrenia and their parents or carers. Ensure that:

- such changes, especially discharge and transfer from child and adolescent mental health services (CAMHS) to adult services, or to primary care, are discussed and planned carefully beforehand with the child or young person and their parents or carers, and are structured and phased
- the care plan supports effective collaboration with social care and other care providers during endings and transitions, and includes details of how to access services in times of crisis
- when referring a child or young person for an assessment in other services (including for psychological interventions), they are supported during the referral period and arrangements for support are agreed beforehand with them.<sup>20</sup>

## **1.2 *Children and young people with possible psychosis***

### **Referral from primary care**

1.2.1 When a child or young person experiences transient psychotic symptoms or other experiences suggestive of possible psychosis, refer for assessment without delay to a specialist mental health service such as CAMHS or an early intervention in psychosis service (14 years and over).

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<sup>20</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).  
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### **Assessment in specialist mental health services**

1.2.2 Carry out an assessment of the child or young person with possible psychosis, ensuring that:

- assessments in CAMHS include a consultant psychiatrist
- assessments in early intervention in psychosis services are multidisciplinary
- where there is considerable uncertainty about the diagnosis, or concern about underlying neurological illness, there is an assessment by a consultant psychiatrist with training in child and adolescent mental health.

1.2.3 If a clear diagnosis of psychosis cannot be made, monitor regularly for further changes in symptoms and functioning for up to 3 years. Determine the frequency and duration of monitoring by:

- the severity and frequency of symptoms
- the level of impairment and/or distress in the child or young person, and
- the degree of family disruption or concern.

1.2.4 If discharge from the service is requested, offer follow-up appointments and the option to self-refer at a later date. Ask the GP to continue monitoring changes in mental state.

## **Treatment options for symptoms not sufficient for a diagnosis of psychosis or schizophrenia**

1.2.5 When transient or attenuated psychotic symptoms or other mental state changes are not sufficient for a diagnosis of psychosis or schizophrenia, consider:

- treatments recommended in NICE guidance for any recognised conditions such as anxiety, depression, emerging personality disorder or substance misuse, or
- individual or family cognitive behavioural therapy (CBT) to decrease distress (delivered as set out in recommendation 1.3.27).

1.2.6 Do not offer antipsychotic medication for psychotic symptoms or mental state changes that are not sufficient for a diagnosis of psychosis or schizophrenia, or with the aim of decreasing the risk of psychosis.

### **1.3 *First episode psychosis***

#### **Referral from primary care**

1.3.1 Urgently refer all children and young people with a first presentation of sustained psychotic symptoms (lasting 4 weeks or more) to a consultant psychiatrist with training in child and adolescent mental health in a specialist mental health service, either in CAMHS or an early intervention in psychosis service (14 years or over).

#### **Assessment and care planning in secondary care**

1.3.2 When carrying out an assessment:

- ensure there is enough time for:
  - the child or young person and their parents or carers to describe and discuss their problems
  - summarising the conclusions of the assessment and for discussion, with questions and answers

- explain and give written material in an accessible format about any diagnosis given
- give information about different treatment options, including pharmacological and psychological interventions, and their side effects, to promote discussion and shared understanding
- offer support after the assessment, particularly if sensitive issues, such as childhood trauma, have been discussed.<sup>21</sup>

1.3.3 Ensure that children and young people with first episode psychosis receive a comprehensive multidisciplinary assessment. The assessment should address the following domains:

- psychiatric (mental health problems, risk of harm to self or others, alcohol consumption and prescribed and non-prescribed drug history)
- psychological and psychosocial, including social networks and relationships
- developmental (social, cognitive and motor development and skills, including coexisting neurodevelopmental conditions)
- physical health and history (including weight and height, and information about smoking, diet and exercise, and sexual health)
- social (accommodation, culture and ethnicity, leisure activities and recreation, carer responsibilities [for example, of parents or siblings])
- educational and occupational (attendance at school or college, educational attainment, employment and functional activity)
- economic (family's economic status).

1.3.4 Routinely monitor for other coexisting mental health problems, including depression and anxiety, and substance misuse, particularly in the early phases of treatment.<sup>22</sup>

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<sup>21</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

<sup>22</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

1.3.5 Develop a care plan with the parents or carers of younger children, or jointly with the young person and their parents or carers, as soon as possible, and:

- include activities that promote physical health and social inclusion, especially education, but also employment, volunteering and other occupations such as leisure activities
- provide support to help the child or young person and their parent or carer realise the plan
- give an up-to-date written copy of the care plan to the young person and their parents or carers if the young person agrees to this; give a copy of the care plan to the parents or carers of younger children; agree a suitable time to review it
- send a copy to the primary healthcare professional who made the referral.<sup>23</sup>

1.3.6 Support children and young people to develop strategies, including risk- and self-management plans, to promote and maintain independence and self-efficacy, wherever possible. Incorporate these strategies into the care plan.<sup>24</sup>

1.3.7 If the child or young person is at risk of crisis, develop a crisis plan with the parents or carers of younger children, or jointly with the young person and their parents or carers, and with their care coordinator. The plan should be respected and implemented, incorporated into the care plan and include:

- possible early warning signs of a crisis and coping strategies
- support available to help prevent hospitalisation
- where the child or young person would like to be admitted in the event of hospitalisation

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<sup>23</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

<sup>24</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

- definitions of the roles of primary and secondary care professionals and the degree to which parents or carers are involved
- information about 24-hour access to services
- the names of key clinical contacts.<sup>25</sup>

1.3.8 For children and young people with first episode psychosis who are unable to attend school or college, facilitate alternative educational input in line with their capacity to engage with educational activity. Where necessary, liaise with the school and education authority to provide education at home.

1.3.9 If the child or young person and/or their parent or carer is unhappy about the assessment, diagnosis or care plan, give them time to discuss this and offer them the opportunity for a second opinion.<sup>26</sup>

### **Treatment options for first episode psychosis**

1.3.10 For children and young people with first episode psychosis offer:

- oral antipsychotic medication (see recommendations 1.3.13–1.3.23) and
- a psychological intervention; family intervention or individual CBT (delivered as set out in recommendations 1.3.25–1.3.31).

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<sup>25</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

<sup>26</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

- 1.3.11 If the child or young person and their parents or carers wish to try a psychological intervention alone (family intervention or individual CBT), inform them that there is little evidence that psychological interventions are effective without antipsychotic medication. Agree a time limit (1 month or less) for reviewing treatment options, including introducing antipsychotic medication. Continue to monitor symptoms, level of distress, impairment and level of functioning, including educational engagement and achievement, regularly.
- 1.3.12 If the child or young person shows symptoms and behaviour sufficient for a diagnosis of an affective psychosis or disorder, including bipolar disorder and unipolar psychotic depression, follow the recommendations in 'Bipolar disorder' (NICE clinical guideline 38) or 'Depression in children and young people' (NICE clinical guideline 28).

#### **Choice of antipsychotic medication**

- 1.3.13 The choice of antipsychotic medication should be made by the parents or carers of younger children, or jointly with the young person and their parents or carers, and healthcare professionals. Provide age-appropriate information and discuss the likely benefits and possible side effects of each drug including:
- metabolic (including weight gain and diabetes)
  - extrapyramidal (including akathisia, dyskinesia and dystonia)
  - cardiovascular (including prolonging the QT interval)
  - hormonal (including increasing plasma prolactin)
  - other (including unpleasant subjective experiences).

### **How to use oral antipsychotic medication<sup>2728</sup>**

1.3.14 Before starting antipsychotic medication, undertake and record the following baseline investigations:

- weight and height (both plotted on a growth chart)
- waist and hip circumference
- pulse and blood pressure
- fasting blood glucose, glycosylated haemoglobin (HbA<sub>1c</sub>), blood lipid profile and prolactin levels
- assessment of any movement disorders
- assessment of nutritional status, diet and level of physical activity.

1.3.15 Before starting antipsychotic medication, offer the child or young person an electrocardiogram (ECG) if:

- specified in the SPC for adults and/or children
- a physical examination has identified specific cardiovascular risk (such as diagnosis of high blood pressure)
- there is personal history of cardiovascular disease
- there is a family history of cardiovascular disease such as sudden cardiac death or prolonged QT interval, or
- the child or young person is being admitted as an inpatient.<sup>29</sup>

1.3.16 Treatment with antipsychotic medication should be considered an explicit individual therapeutic trial. Include the following:

- From a discussion with the child or young person and their parent or carer, record the side effects the child or young person is most and least willing to tolerate.

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<sup>27</sup> See Appendix B for a table of baseline investigations and monitoring for children and young people who are prescribed antipsychotic medication (read in conjunction with the BNF, BNFC and SPC).

<sup>28</sup> At the time of consultation (August 2012), most antipsychotic medication did not have a UK marketing authorisation specifically for children and young people. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Good practice in prescribing medicines – guidance for doctors](#) for further information.

<sup>29</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

- Record the indications and expected benefits and risks of oral antipsychotic medication, and the expected time for a change in symptoms and appearance of side effects.
- At the start of treatment give a dose below the lower end of the licensed range for adults if the drug is not licensed for children and young people and at the lower end of the licensed range if the drug is licensed for children and young people; slowly titrate upwards within the dose range given in the British national formulary (BNF), the British national formulary for children (BNFC) or the SPC.
- Justify and record reasons for dosages above the range given in the BNF, BNFC or SPC.
- Record the rationale for continuing, changing or stopping medication, and the effects of such changes.
- Carry out a trial of the medication at optimum dosage for 4–6 weeks.<sup>30</sup>

1.3.17 Monitor and record the following regularly and systematically throughout treatment, but especially during titration:

- efficacy, including changes in symptoms and behaviour
- side effects of treatment, taking into account overlap between certain side effects and clinical features of schizophrenia (for example, the overlap between akathisia and agitation or anxiety)
- the emergence of movement disorders
- weight, weekly for the first 6 weeks, then at 12 weeks and then every 6 months thereafter (plotted on a growth chart)
- height every 6 months (plotted on a growth chart)
- waist and hip circumference every 6 months (plotted on a percentile chart)
- pulse and blood pressure (plotted on a percentile chart) at 12 weeks and then every 6 months thereafter

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<sup>30</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

- fasting blood glucose, HbA<sub>1c</sub>, blood lipid and prolactin levels at 12 weeks and then every 6 months thereafter
- adherence
- physical health.

The secondary care team should maintain responsibility for physical monitoring of antipsychotic medication for at least the first 12 months or until the child or young person's condition has stabilised. Thereafter, the responsibility for physical monitoring may be transferred to primary care under shared care arrangements.

- 1.3.18 Discuss any non-prescribed therapies that children or young people, or their parents or carers, wish to use (including complementary therapies) with them. Discuss the safety and efficacy of the therapies, and possible interference with the therapeutic effects of prescribed medication and psychological interventions.<sup>31</sup>
- 1.3.19 Discuss the use of alcohol, tobacco, prescription and non-prescription medication and illicit drugs with the child or young person, and their parents or carers where this has been agreed. Discuss their possible interference with the therapeutic effects of prescribed medication and psychological interventions and the potential of illicit drugs to exacerbate psychotic symptoms.<sup>32</sup>
- 1.3.20 'As required' (p.r.n.) prescriptions of antipsychotic medication should be made as described in recommendation 1.3.16. Review clinical indications, frequency of administration, therapeutic benefits and side effects at least weekly. Check whether 'p.r.n.' prescriptions have led to a dosage above the maximum specified in the BNF, BNFC or SPC.<sup>33</sup>

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<sup>31</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>32</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>33</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

- 1.3.21 Do not use a loading dose of antipsychotic medication (often referred to as ‘rapid neuroleptisation’).<sup>34</sup>
- 1.3.22 Do not initiate regular combined antipsychotic medication, except for short periods (for example, when changing medication).<sup>35</sup>
- 1.3.23 If prescribing chlorpromazine<sup>36</sup>, warn of its potential to cause skin photosensitivity. Advise using sunscreen if necessary.<sup>37</sup>
- 1.3.24 Review antipsychotic medication annually, including observed benefits and any side effects.

### **How to deliver psychological interventions**

- 1.3.25 When delivering psychological interventions for children and young people with psychosis or schizophrenia, take into account their developmental level, emotional maturity and cognitive capacity, including any learning disabilities, sight or hearing problems or delays in language development.
- 1.3.26 Family intervention should:
- include the child or young person with psychosis or schizophrenia if practical
  - be carried out for between 3 months and 1 year
  - include at least 10 planned sessions
  - take account of the whole family's preference for either single-family intervention or multi-family group intervention
  - take account of the relationship between the parent or carer and the child or young person with psychosis or schizophrenia

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<sup>34</sup> Adapted from ‘Schizophrenia’ (NICE clinical guideline 82).

<sup>35</sup> Adapted from ‘Schizophrenia’ (NICE clinical guideline 82).

<sup>36</sup> At the time of consultation (August 2012), chlorpromazine did not have a UK marketing authorisation for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council’s [Good practice in prescribing medicines – guidance for doctors](#) for further information..

<sup>37</sup> Adapted from ‘Schizophrenia’ (NICE clinical guideline 82).

- have a specific supportive, educational or treatment function and include negotiated problem solving or crisis management work.<sup>38</sup>

1.3.27 CBT should be delivered on a one-to-one basis over at least 16 planned sessions (although longer may be needed) and:

- follow a treatment manual<sup>39</sup> so that:
  - children and young people can establish links between their thoughts, feelings or actions and their current or past symptoms, and/or functioning
  - the re-evaluation of the child or young person's perceptions, beliefs or reasoning relates to the target symptoms
- also include at least one of the following components:
  - normalising, leading to understanding and acceptability of their experience
  - children and young people monitoring their own thoughts, feelings or behaviours with respect to their symptoms or recurrence of symptoms
  - promoting alternative ways of coping with the target symptom
  - reducing distress
  - improving functioning.<sup>40</sup>

### **Monitoring and reviewing psychological interventions**

1.3.28 When providing psychological interventions, routinely and systematically monitor a range of outcomes across relevant areas, including the child or young person's satisfaction and, if appropriate, parents' or carers' satisfaction.<sup>41</sup>

1.3.29 Healthcare teams working with children and young people with psychosis or schizophrenia should identify a lead healthcare

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<sup>38</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>39</sup> Treatment manuals that have evidence for their efficacy from clinical trials are preferred. If developed for adults, the manual should be adapted to suit the age and developmental level of the child or young person.

<sup>40</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>41</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

professional within the team whose responsibility is to monitor and review:

- access to and engagement with psychological interventions
- decisions to offer psychological interventions and equality of access across different ethnic groups.<sup>42</sup>

### **Competencies for delivering psychological interventions**

1.3.30 Healthcare professionals delivering psychological interventions should:

- have an appropriate level of competence in delivering the intervention to children and young people with psychosis or schizophrenia
- be regularly supervised during psychological therapy by a competent therapist and supervisor.<sup>43</sup>

1.3.31 Trusts should provide access to training that equips healthcare professionals with the competencies required to deliver the psychological interventions for children and young people recommended in this guideline.<sup>44</sup>

## **1.4 Treatment of subsequent acute episodes of psychosis or schizophrenia**

### **Pharmacological interventions<sup>45</sup>**

1.4.1 For children or young people with an acute exacerbation or recurrence of psychosis or schizophrenia, offer oral antipsychotic medication or review existing medication. The choice of drug should be influenced by the same criteria recommended for starting

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<sup>42</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>43</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>44</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>45</sup> At the time of consultation (August 2012), most antipsychotic medication did not have a UK marketing authorisation specifically for children and young people. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Good practice in prescribing medicines – guidance for doctors](#) for further information.

treatment (see recommendations 1.3.14–1.3.243). Take into account the clinical response to and side effects associated with current and previous medication, and monitor as described in recommendation 1.3.17.<sup>46</sup>

- 1.4.2 Aripiprazole is recommended as an option for the treatment of schizophrenia in people aged 15 to 17 years who are intolerant of risperidone, or for whom risperidone is contraindicated, or whose schizophrenia has not been adequately controlled with risperidone. [This recommendation is from ‘Aripiprazole for the treatment of schizophrenia in people aged 15 to 17 years’ (NICE technology appraisal guidance 213).]
- 1.4.3 People aged 15 to 17 years currently receiving aripiprazole for the treatment of schizophrenia who do not meet the criteria specified in 1.4.2 should have the option to continue treatment until it is considered appropriate to stop. This decision should be made jointly by the clinician and the person with schizophrenia, and if appropriate, their parents or carers. [This recommendation is from ‘Aripiprazole for the treatment of schizophrenia in people aged 15 to 17 years’ (NICE technology appraisal guidance 213).]

### **Psychological and psychosocial interventions**

- 1.4.4 Offer family intervention<sup>47</sup> to all families of children and young people with psychosis or schizophrenia, particularly for preventing and reducing relapse. This can be started either during the acute phase or later, including in inpatient settings.<sup>48</sup>
- 1.4.5 Offer CBT<sup>49</sup> to all children and young people with psychosis or schizophrenia, particularly for symptom reduction. This can be

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<sup>46</sup> Adapted from ‘Schizophrenia’ (NICE clinical guideline 82).

<sup>47</sup> Family intervention should be delivered as described in recommendation 1.3.26.

<sup>48</sup> Adapted from ‘Schizophrenia’ (NICE clinical guideline 82).

<sup>49</sup> CBT should be delivered as described in recommendation 1.3.27.

started either during the acute phase or later, including in inpatient settings.<sup>50</sup>

- 1.4.6 Consider arts therapies (for example, dance movement, drama, music or art therapy) for all children and young people with psychosis or schizophrenia, particularly for the alleviation of negative symptoms. This can be started either during the acute phase or later, including in inpatient settings.<sup>51</sup>
- 1.4.7 If arts therapies are considered, they should be provided by Health Professions Council (HPC) registered arts therapists, with experience of working with children and young people with psychosis or schizophrenia. The intervention should be provided in groups unless difficulties with acceptability and access and engagement indicate otherwise. Arts therapies should combine psychotherapeutic techniques with activity aimed at promoting creative expression, which is often unstructured and led by the child or young person. Aims of arts therapies should include:
- enabling children and young people with psychosis or schizophrenia to experience themselves differently and to develop new ways of relating to others
  - helping children and young people to express themselves and to organise their experience into a satisfying aesthetic form
  - helping children and young people to accept and understand feelings that may have emerged during the creative process (including, in some cases, how they came to have these feelings) at a pace suited to them.<sup>52</sup>
- 1.4.8 Do not routinely offer counselling and supportive psychotherapy (as specific interventions) to children and young people with psychosis or schizophrenia. However, take the child or young person's and their parents' or carers' preferences into account, especially if other

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<sup>50</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>51</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>52</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

more efficacious psychological interventions, such as CBT, family intervention and arts therapies, are not available locally.<sup>53</sup>

1.4.9 Do not offer adherence therapy (as a specific intervention) to children and young people with psychosis or schizophrenia.<sup>54</sup>

1.4.10 Do not routinely offer social skills training (as a specific intervention) to children and young people with psychosis or schizophrenia.<sup>55</sup>

1.4.11 When psychological interventions, including arts therapies, are started in the acute phase (including in inpatient settings), the full course should be continued after discharge without unnecessary interruption.<sup>56</sup>

### **Referral in crisis**

1.4.12 When a child or young person is referred in crisis they should be seen by specialist mental health secondary care services within 4 hours of referral.<sup>57</sup>

1.4.13 To avoid admission, aim to:

- explore with the child or young person and their parents or carers what support systems they have, including other family members and friends
- support a child or young person in crisis and their parents or carers in their home environment
- make early plans to help the child or young person maintain their day-to-day activities, including education, work, and other occupations and leisure activities, wherever possible.<sup>58</sup>

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<sup>53</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>54</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>55</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>56</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>57</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

<sup>58</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

- 1.4.14 At the end of a crisis assessment, ensure that the decision to start home treatment depends not on the diagnosis, but on:
- the level of distress
  - the severity of the problems
  - the vulnerability of the child or young person and issues of safety and support at home
  - the child or young person's cooperation with treatment.<sup>59</sup>
- 1.4.15 Consider the support and care needs of parents or carers of children or young people in crisis. Where needs are identified, ensure they are met when it is safe and practicable to do so.<sup>60</sup>

### **Hospital care**

- 1.4.16 If a child or young person needs hospital care, this should be in setting appropriate to their age and developmental level.
- 1.4.17 Before referral for hospital care, think about the impact on the child or young person and their parents, carers and other family members, especially when the inpatient unit is a long way from where they live. Consider alternative care within the community wherever possible. If hospital admission is unavoidable, provide support for parents or carers when the child or young person is admitted.
- 1.4.18 Give verbal and written information to children and young people with psychosis or schizophrenia admitted to hospital, and their parents or carers, about:

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<sup>59</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

<sup>60</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

- the hospital and the ward in which the child or young person will stay
- treatments, activities and services available
- expected contact from health and social care professionals
- rules of the ward (including substance misuse policy)
- their rights, responsibilities and freedom to move around the ward and outside
- meal times
- visiting arrangements.

Make sure there is enough time for the child or young person and their parents or carers to ask questions.<sup>61</sup>

- 1.4.19 Undertake shared decision-making routinely with children or young people with psychosis or schizophrenia in hospital, including, whenever possible, those who are subject to the Mental Health Act (1983; amended 1995 and 2007).<sup>62</sup>
- 1.4.20 Ensure that children and young people of compulsory school age have access to a full educational programme while in hospital. The programme should meet the National Curriculum, be matched to the child or young person's developmental level and educational attainment, and should take account of their illness and degree of impairment.
- 1.4.21 Ensure that children and young people in hospital continue to have access to a wide range of meaningful and culturally appropriate occupations and activities 7 days per week, and not restricted to 9am to 5pm. These should include creative and leisure activities, exercise, self-care and community access activities (where appropriate). Activities should be facilitated by appropriately trained educational, health or social care professionals.<sup>63</sup>

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<sup>61</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

<sup>62</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

<sup>63</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

1.4.22 Children and young people receiving community care before hospital admission should be routinely visited while in hospital by the health and social care professionals responsible for their community care.<sup>64</sup>

1.4.23 Promote good physical health, including healthy eating, exercise and smoking cessation.

### **Rapid tranquillisation and restraint**

1.4.24 Healthcare professionals undertaking rapid tranquillisation or restraint in children and young people with psychosis or schizophrenia should be trained and competent in undertaking these procedures in children and young people.

1.4.25 Occasionally children and young people with psychosis or schizophrenia pose an immediate risk to themselves or others during an acute episode and may need rapid tranquillisation. Be particularly cautious when considering high-potency antipsychotic medication (such as haloperidol) in children and young people, especially those who have not taken antipsychotic medication before, because of the increased risk of acute dystonic reactions in that age group.<sup>65</sup>

1.4.26 After rapid tranquillisation, offer the child or young person the opportunity to discuss their experiences. Provide them with a clear explanation of the decision to use urgent sedation. Record this in their notes.<sup>66</sup>

1.4.27 Follow the recommendations in 'Self-harm' (NICE clinical guideline 16) when managing acts of self-harm in children and young people with psychosis or schizophrenia.<sup>67</sup>

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<sup>64</sup> Adapted from 'Service user experience in adult mental health' (NICE clinical guideline 136).

<sup>65</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>66</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>67</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

## **1.5 *Early post-acute period***

- 1.5.1 In the early period of recovery following an acute episode, reflect upon the episode and its impact with the child or young person and their parents or carers, and make plans for recovery and possible future care.
- 1.5.2 Inform the child or young person and their parents or carers that there is a high risk of relapse if medication is stopped in the 1–2 years following an acute episode.<sup>68</sup>
- 1.5.3 If withdrawing antipsychotic medication, undertake gradually and monitor regularly for signs and symptoms of relapse.<sup>69</sup>
- 1.5.4 After withdrawal from antipsychotic medication, continue monitoring for signs and symptoms of relapse for at least 2 years.<sup>70</sup>

## **1.6 *Promoting recovery and providing possible future care***

### **Primary care**

- 1.6.1 Develop and use practice case registers to monitor the physical and mental health of children and young people with psychosis or schizophrenia in primary care.<sup>71</sup>
- 1.6.2 GPs and other primary healthcare professionals should monitor the physical health of children and young people with psychosis or schizophrenia at least once a year. They should bear in mind that people with schizophrenia are at higher risk of cardiovascular disease than the general population.
- 1.6.3 Children and young people with psychosis or schizophrenia at increased risk of developing cardiovascular disease and/or diabetes (for example, with elevated blood pressure, raised lipid

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<sup>68</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>69</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>70</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>71</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

levels, smokers, increased waist measurement) should be identified at the earliest opportunity and monitored for the emergence of these conditions.

- 1.6.4 Treat children and young people with psychosis or schizophrenia who have diabetes and/or cardiovascular disease in primary care according to the appropriate NICE guidance where available<sup>72 73</sup>.
- 1.6.5 Healthcare professionals in secondary care should ensure, as part of the care programme approach (CPA), that children and young people with psychosis or schizophrenia receive physical healthcare from primary care as described in recommendations 1.6.2–1.6.4. Healthcare professionals in secondary care should continue to maintain responsibility for monitoring and managing any side effects of antipsychotic medication.<sup>74</sup>
- 1.6.6 When a child or young person with a diagnosis of psychosis or schizophrenia presents with a suspected relapse (for example, with increased psychotic symptoms or a significant increase in the use of alcohol or other substances) and is still receiving treatment, primary healthcare professionals should refer to the crisis section of the care plan. Consider referral to the key clinician or care coordinator identified in the crisis plan.<sup>75</sup>
- 1.6.7 For a child or young person with psychosis or schizophrenia being cared for in primary care, consider referral to secondary care again if there is:
- poor response to treatment
  - non-adherence to medication
  - intolerable side effects from medication or the child or young person or their parents or carers request a review of side effects

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<sup>72</sup>See 'Type 1 diabetes' (NICE clinical guideline 15).

<sup>73</sup>Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>74</sup>Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>75</sup>Adapted from 'Schizophrenia' (NICE clinical guideline 82).

- the child or young person or their parents or carers request psychological interventions not available in primary care
- comorbid substance misuse
- risk to self or others.<sup>76</sup>

1.6.8 Children and young people with psychosis or schizophrenia who are being treated in an early intervention in psychosis service should remain in that service for 3 years whatever their age of entry.

### **Psychological interventions**

1.6.9 Offer family intervention to families of children and young people with psychosis or schizophrenia. Deliver family intervention as described in recommendation 1.3.26.<sup>77</sup>

1.6.10 Consider family intervention particularly for families of children and young people with psychosis or schizophrenia who have:

- recently relapsed or are at risk of relapse
- persisting symptoms.<sup>78</sup>

1.6.11 Offer CBT to assist in promoting recovery in children and young people with persisting positive and negative symptoms and for those in remission. Deliver CBT as described in recommendation 1.3.27.<sup>79</sup>

1.6.12 Consider arts therapies (see recommendation 1.4.76) to assist in promoting recovery, particularly in children and young people with negative symptoms.<sup>80</sup>

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<sup>76</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>77</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>78</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>79</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>80</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

### **Pharmacological interventions<sup>81</sup>**

- 1.6.13 The choice of drug should be influenced by the same criteria recommended for starting treatment (see recommendations 1.3.14–1.3.243).<sup>82</sup>
- 1.6.14 Do not use targeted, intermittent dosage maintenance strategies<sup>83</sup> routinely. However, consider them for children and young people with psychosis or schizophrenia who are unwilling to accept a continuous maintenance regimen or if there is another contraindication to maintenance therapy, such as side-effect sensitivity.<sup>84</sup>

### **Interventions for children and young people with psychosis or schizophrenia whose illness has not responded adequately to treatment<sup>85</sup>**

- 1.6.15 For children and young people with psychosis or schizophrenia whose illness has not responded adequately to pharmacological or psychological interventions:
- review the diagnosis
  - establish that there has been adherence to antipsychotic medication, prescribed at an adequate dose and for the correct duration
  - review engagement with and use of psychological interventions and ensure that these have been offered according to this guideline; if family intervention has been undertaken suggest

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<sup>81</sup> At the time of consultation (August 2012), most antipsychotic medication did not have a UK marketing authorisation specifically for children and young people. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Good practice in prescribing medicines – guidance for doctors](#) for further information.

<sup>82</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>83</sup> Defined as the use of antipsychotic medication only during periods of incipient relapse or symptom exacerbation rather than continuously.

<sup>84</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>85</sup> At the time of consultation (August 2012), most antipsychotic medication did not have a UK marketing authorisation specifically for children and young people. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Good practice in prescribing medicines – guidance for doctors](#) for further information.

CBT; if CBT has been undertaken suggest family intervention for children and young people in close contact with their families

- consider other causes of non-response, such as comorbid substance misuse (including alcohol), the concurrent use of other prescribed medication or physical illness.<sup>86</sup>

1.6.16 Offer clozapine<sup>87</sup> to children and young people whose illness has not responded adequately to pharmacological treatment despite the sequential use of adequate doses of at least two different antipsychotic drugs.<sup>88</sup>

1.6.17 For children and young people whose illness has not responded adequately to clozapine<sup>89</sup> at an optimised dose, consider a multidisciplinary review, and recommendation 1.6.15 (including measuring therapeutic drug levels) before adding a second antipsychotic to augment treatment with clozapine. An adequate trial of such an augmentation may need to be up to 8–10 weeks. Choose a drug that does not compound the common side effects of clozapine.<sup>90</sup>

### **Education, employment and occupational activities**

1.6.18 For children and young people of compulsory school age, liaise with the child or young person's school and educational authority to ensure that ongoing education is provided.

1.6.19 Liaise with the child or young person's school and with their parents or carers to determine whether a special educational needs assessment is necessary. If it is agreed that this is needed, explain

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<sup>86</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>87</sup> At the time of consultation (August 2012), clozapine did not have a UK marketing authorisation for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Good practice in prescribing medicines – guidance for doctors](#) for further information.

<sup>88</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>89</sup> At the time of consultation (August 2012), clozapine did not have a UK marketing authorisation for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Good practice in prescribing medicines – guidance for doctors](#) for further information.

<sup>90</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

to parents or carers how to apply for an assessment and offer support throughout the process.

- 1.6.20 Provide supported employment programmes for those young people with psychosis or schizophrenia above compulsory school age who wish to return to work or find employment. Consider other work-related activities and programmes when individuals are unable to work or are unsuccessful in their attempts to find employment.<sup>91</sup>
- 1.6.21 Mental health services should work in partnership with local stakeholders, including those representing black and minority ethnic groups, to enable young people with psychosis or schizophrenia to access local employment and educational opportunities. This should be sensitive to the young person's needs and skill level and is likely to involve working with agencies such as Jobcentre Plus, disability employment advisers and non-statutory providers.<sup>92</sup>
- 1.6.22 Routinely record the daytime activities of children and young people with psychosis or schizophrenia in their care plans, including educational and occupational outcomes.<sup>93</sup>

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<sup>91</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>92</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

<sup>93</sup> Adapted from 'Schizophrenia' (NICE clinical guideline 82).

## 2 Notes on the scope of the guidance

NICE guidelines are developed in accordance with a scope that defines what the guideline will and will not cover. The scope of this guideline is available [here](#).

### How this guideline was developed

NICE commissioned the National Collaborating Centre for Mental Health to develop this guideline. The Centre established a Guideline Development Group (see appendix A), which reviewed the evidence and developed the recommendations.

There is more information about [how NICE clinical guidelines are developed](#) on the NICE website. A booklet, 'How NICE clinical guidelines are developed: an overview for stakeholders, the public and the NHS' is [available](#).

## 3 Implementation

NICE has developed [tools to help organisations implement this guidance](#).

**Note: these details will apply when the guideline is published.**

## 4 Research recommendations

The Guideline Development Group has made the following recommendations for research, based on its review of evidence, to improve NICE guidance and patient care in the future. The Guideline Development Group's full set of research recommendations is detailed in the full guideline (see section 5).

**4.1 *What are the long-term outcomes, both psychotic and non-psychotic, for children and young people with prodromal symptoms suggestive of a developing psychosis, and can the criteria for ‘at risk states’ be refined to better predict those who will and those who will not go on to develop psychosis?***

The suggested programme of research would be in two phases. First, a systematic review and meta-analysis of prospective observational studies/cohorts of children and young people identified at high or ultra-high risk of developing psychosis would be undertaken. The review would identify risk and protective factors most strongly associated with the later development of psychotic and non-psychotic outcomes. Second, the factors identified in the first phase would be used to identify a large cohort of children and young people with these factors and to evaluate the effectiveness of these refined criteria for predicting the later development of psychotic and non-psychotic outcomes.

**Why this is important**

A major problem with trials of treatments for populations of children and young people deemed to be ‘at risk’ or ‘at ultra-high risk’ of developing psychosis is identifying the precise symptoms and/or behaviours or (risk) factors that are most strongly associated with the development of psychosis; and conversely, which (protective) factors are likely to be associated with a lowered risk of later psychosis. At present, identified factors have a low predictive value, with only about 10-20% of children and young people who have been identified as at high risk going on to develop psychosis. If these risk and protective factors could be refined, it would be possible to better target children and young people who are most at risk, and reduce the numbers of those thought to be ‘at risk’ who do not go on to later develop psychosis.

**4.2 *What is the clinical and cost effectiveness of omega-3 fatty acids in the treatment of children and young***

***people considered to be at high risk of developing psychosis?***

The suggested programme of research would need to test out, using an adequately powered, multicentre randomised controlled design, the likely benefits and costs of using omega-3 fatty acids for children and young people at high risk of developing psychosis. The outcomes considered should include transition to psychosis, quality of life, symptomatic and functional improvements, treatment acceptability, side effects and self-harm. There should be follow-up at 3 years. The trial should also estimate the cost-effectiveness of intervening.

**Why this is important**

A number of interventions have been trialled in an attempt to avert the development of psychosis, including drugs, psychological treatments and other interventions. A relatively recent, moderate-sized RCT of omega-3 fatty acids has shown the best evidence of any intervention, to date, at reducing the rates of transition from 'high risk' states to a sustained psychosis. However, this is a single trial, which is underpowered, undertaken in one centre and lacks any health economic analysis.

**4.3 *What is the clinical and cost effectiveness for family intervention combined with individual CBT in the treatment of children and young people considered to be at high risk of developing psychosis and their parents or carers?***

The suggested programme of research would need to test out, using an adequately powered, multicentre, randomised controlled design, the likely benefits and costs of providing family intervention, combined with individual CBT, for children and young people at high risk of developing psychosis for and their parents or carers. The outcomes considered should include transition to psychosis, quality of life, symptomatic and functional improvements, treatment acceptability and self-harm. There should be follow-

up at 3 years. The trial should also estimate the cost effectiveness of intervening.

### **Why this is important**

A number of interventions have been trialled in an attempt to avert the development of psychosis, including drugs, psychological treatments and other interventions. After the first episode of schizophrenia, family intervention as an adjunct to antipsychotic medication substantially and significantly reduces relapse rates. A single small trial combining CBT family treatment with individual CBT without antipsychotic treatment suggested an important reduction in transition rates to the first psychosis.

## **4.4 *What is the clinical and cost effectiveness of psychological treatment alone, compared with antipsychotic medication and compared with psychological treatment and antipsychotic medication combined, for young people with first episode psychosis?***

The programme of research would compare the clinical and cost effectiveness of psychological treatment alone, compared with antipsychotic medication, and compared with psychological treatment, and antipsychotic medication combined, for young people with in the early stages of schizophrenia using an randomised controlled design and adequately powered. The combination of psychological treatments most likely to have an impact would be family intervention and individual CBT. The key outcomes should include symptoms, relapse rates, quality of life, treatment acceptability, experience of care, level of psychosocial functioning and the cost effectiveness of the interventions.

### **Why this is important**

The personal and financial cost of established schizophrenia to the individual, to their family and friends, and to society is considerable. The personal cost is reflected in a suicide rate of nearly 15% amongst people with schizophrenia, and a lifelong unemployment rate that varies between 50 and 75%, depending on geographical location, and reduced life expectancy. The additional cost to

the healthcare system for one person with schizophrenia is estimated to reach over £50,000 per year, on average, throughout their life.

Currently, the mainstay of treatment is antipsychotic medication, but the side effects are so severe that there is considerable impetus to develop alternative treatment strategies. It has been recognised that psychological treatments as an adjunct to antipsychotic medication have an important part to play in the treatment of schizophrenia. The first NICE guideline identified family intervention and CBT as adjunctive treatments and current evidence suggests that these interventions are cost saving. There has been one recent positive trial of CBT as a first-line treatment, without antipsychotics, for young people with in the early stages of schizophrenia.

#### **4.5 *What is the clinical effectiveness of clozapine for children and young people with schizophrenia with symptoms unresponsive to antipsychotic medication and psychological treatment combined?***

The suggested programme of research would need to test out, using an adequately powered, RCT-design, the likely benefits of using clozapine, compared with another antipsychotic, for children and young people with symptoms of schizophrenia unresponsive to antipsychotic medication and psychological treatment combined. The outcomes considered should include quality of life, symptomatic and functional improvements, treatment acceptability, side effects and length of hospitalisation.

#### **Why this is important**

Currently, about 30% of people with schizophrenia have symptoms that do not respond adequately to treatment with an antipsychotic. Although precise figures are unavailable, especially for children and young people, smaller percentages of people do not respond when a second, alternative, antipsychotic and an adequate course of psychological treatment have been tried. For these people, clozapine, which has a different dopamine receptor subtype blocking profile from other antipsychotics, has become an important treatment option in adults. However, evidence is lacking (only one study)

about the effectiveness of clozapine for 'treatment-resistant schizophrenia' in children and young people.

## 5 Other versions of this guideline

### 5.1 *Full guideline*

The full guideline, ['Full guideline title' (in quotes, no italics)] contains details of the methods and evidence used to develop the guideline. It is published by the National Collaborating Centre for Mental Health, and is available from [our website](#). **Note: these details will apply to the published full guideline.**

### 5.2 *NICE pathway*

The recommendations from this guideline have been incorporated into a [NICE pathway](#). **Note: these details will apply when the guideline is published.**

### 5.3 *'Understanding NICE guidance'*

A summary for patients and carers (['Understanding NICE guidance'](#)) is available.

For printed copies, phone NICE publications on 0845 003 7783 or email [publications@nice.org.uk](mailto:publications@nice.org.uk) (quote reference number N[XXXX]). **Note: these details will apply when the guideline is published.**

We encourage NHS and voluntary sector organisations to use text from this booklet in their own information about psychosis and schizophrenia in children and young people.

## 6 Related NICE guidance

### Published

- [Service user experience in adult mental health](#). NICE clinical guideline 136 (2011).
- [Aripiprazole for the treatment of schizophrenia in people aged 15 to 17 years](#). NICE technology appraisal 213 (2011).
- [Alcohol-use disorders](#). NICE clinical guideline 115. (2011)

- [Schizophrenia](#). NICE clinical guideline 82 (2009).
- [Borderline personality disorder](#). NICE clinical guideline 78 (2009).
- [Antisocial personality disorder](#). NICE clinical guideline 77 (2009).
- [Drug misuse: opioid detoxification](#). NICE clinical guideline 52 (2007).
- [Drug misuse: psychosocial interventions](#). NICE clinical guideline 51 (2007).
- [Obesity](#). NICE clinical guideline 43 (2006).
- [Bipolar disorder](#). NICE clinical guideline 38 (2006).
- [Statins for the prevention of cardiovascular events](#). NICE technology appraisal guidance 94 (2006).
- [Obsessive-compulsive disorder](#). NICE clinical guideline 31 (2005).
- [Depression in children and young people](#). NICE clinical guideline 28 (2005).
- [Violence](#). NICE clinical guideline 25 (2005).
- [Self-harm](#). NICE clinical guideline 16 (2004).
- [Type 1 diabetes](#). NICE clinical guideline 15 (2004).

### **Under development**

NICE is developing the following guidance (details available from [the NICE website](#)):

- Bipolar disorder (update). NICE clinical guideline. Publication date to be confirmed.

## **7 Updating the guideline**

NICE clinical guidelines are updated so that recommendations take into account important new information. New evidence is checked 3 years after publication, and healthcare professionals and patients are asked for their views; we use this information to decide whether all or part of a guideline needs updating. If important new evidence is published at other times, we may decide to do a more rapid update of some recommendations. Please see our website for information about updating the guideline.

## **Appendix A: The Guideline Development Group, National Collaborating Centre and NICE project team**

### ***Guideline Development Group***

#### **Professor Chris Hollis (Chair, Guideline Development Group)**

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Editor

## Appendix B: Baseline investigations and monitoring children and young people who are prescribed antipsychotic medication (read in conjunction with the BNF, BNFC and SPC)

	Baseline investigations before starting antipsychotic medication	Monitor weekly for the first 6 weeks	Monitor at 12 weeks	Monitor every 6 months thereafter	Monitor regularly throughout treatment, and especially during titration
Weight (plotted on a growth chart) <sup>a</sup>	✓	✓	✓	✓	
Height (plotted on a growth chart) <sup>a</sup>	✓			✓	
Waist and hip circumference (plotted on a percentile chart)	✓			✓	
Pulse	✓		✓	✓	
Blood pressure (plotted on a percentile chart)	✓		✓	✓	
Fasting blood glucose	✓		✓	✓	
HbA1c (glycosylated haemoglobin)	✓		✓	✓	
Blood lipid profile	✓		✓	✓	
Prolactin level	✓		✓	✓	
Movement disorders (extrapyramidal symptoms, akathisia, dystonia and tardive dyskinesia)	✓				✓ <sup>b</sup>
Nutritional status, diet and level of physical	✓				

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	Baseline investigations before starting antipsychotic medication	Monitor weekly for the first 6 weeks	Monitor at 12 weeks	Monitor every 6 months thereafter	Monitor regularly throughout treatment, and especially during titration
<b>activity</b>					
<b>The side effects the child or young person is most or least willing to tolerate</b>	✓				
<b>ECG</b>	✓ <sup>c</sup>				
<b>Efficacy</b>					✓
<b>Side effects</b>					✓
<b>Adherence</b>					✓
<b>Physical health</b>					✓

<sup>a</sup> Calculate and document BMI (percentile). <sup>b</sup> Even if no baseline assessment (and at each clinic visit if more frequent).

<sup>c</sup> If specified in the SPC for adults and/or children; a physical examination has identified specific cardiovascular risk (such as diagnosis of high blood pressure); there is personal history of cardiovascular disease; there is a family history of cardiovascular disease such as sudden cardiac death or prolonged QT interval; or the child or young person is being admitted as an inpatient.