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

# NICE guideline: short version

# **Draft for consultation, January 2016**

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**This guideline covers** the recognition and management of psychosis and schizophrenia in children and young people (aged 18 or under). It includes recommendations on:

- · referral from primary care
- assessing and treating a first episode of psychosis
- treating subsequent acute episodes of psychosis or schizophrenia
- referral in crisis
- managing the early post-acute period
- promoting recovery.

#### Who is it for?

- 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
- Children and young people with psychosis or schizophrenia, their families and carers

This guideline will update NICE guideline CG155 (published January 2013).

We have added 1 new recommendation on providing information about olanzapine when choosing antipsychotic medication for children and young people with a first episode of psychosis. This is marked as **[new 2016]**. We have reviewed the evidence and made no change to the recommended action in 1 recommendation on

choosing antipsychotic medication for children and young people with a first episode of psychosis. This is marked as **[2016]**. You are invited to comment on these recommendations.

We have not updated recommendations shaded in grey, and cannot accept comments on them.

See update information for a full explanation of what is being updated.

Evidence for the 2013 recommendations is in the <u>full version</u> of the 2013 guideline The supporting information and evidence for the 2016 recommendations is contained in the addendum.

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# 1 Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in <u>your care</u>.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

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- 3 All recommendations relate to children and young people (younger than 18 years)
- 4 unless otherwise specified.

# 1.1 General principles of care

# 6 Working safely and effectively with children and young people

- 1.1.1 Health and social care professionals working with children and young people with psychosis or schizophrenia should be trained and competent to work with children and young people with mental health problems of all levels of learning ability, cognitive capacity, emotional maturity and development. [2013]
- 1.1.2 Health and social care professionals should ensure that they:
  - can assess capacity and competence, including 'Gillick competence', in children and young people of all ages, and
  - understand how to apply legislation, including the Children Act (1989; amended 2004), the Mental Health Act (1983; amended 1995 and 2007<sup>1</sup>) and the Mental Capacity Act (2005), in the care and treatment of children and young people. [2013]
- 1.1.3 Consider children and young people with psychosis or schizophrenia for assessment according to local safeguarding procedures if there are

<sup>&</sup>lt;sup>1</sup> Including the Code of Practice: Mental Health Act 1983.

1		concerns regarding exploitation or self-care, or if they have been in contact with the criminal justice system <sup>2</sup> . <b>[2013]</b>
2		contact with the chiminal justice system. [2013]
3	1.1.4	Health and social care providers should ensure that children and young
4		people with psychosis or schizophrenia:
5 6 7 8		<ul> <li>can routinely receive care and treatment from a single multidisciplinary community team</li> <li>are not passed from one team to another unnecessarily</li> <li>do not undergo multiple assessments unnecessarily<sup>3</sup>. [2013]</li> </ul>
9	1.1.5	Help the child or young person to continue their education. Contact the
10		school or college, subject to consent, to ask for additional educational
11		support if their performance has been affected by their condition. [2013]
12	Establish	ing relationships with children and young people and their parents or
13	carers	
14	1.1.6	Work in partnership with children and young people with psychosis or
15		schizophrenia of an appropriate developmental level, emotional maturity
16		and cognitive capacity and parents or carers. Offer help, treatment and
17		care in an atmosphere of hope and optimism. Take time to build trusting,
18		supportive, empathic and non-judgemental relationships as an essential
19		part of care <sup>4</sup> . [2013]
20	1.1.7	When working with children and young people with psychosis or
21		schizophrenia:
22		aim to foster autonomy, promote active participation in treatment
23		decisions, and support self-management and access to peer support in
24		children and young people of an appropriate developmental level,
25		emotional maturity and cognitive capacity
26		maintain continuity of individual therapeutic relationships wherever
27		possible

<sup>2</sup> Adapted from <u>Service user experience in adult mental health</u> (NICE guideline CG136).

<sup>3</sup> Adapted from <u>Service user experience in adult mental health</u> (NICE guideline CG136).

<sup>4</sup> Adapted from <u>Service user experience in adult mental health</u> (NICE guideline CG136).

1		<ul> <li>offer access to a trained advocate<sup>5</sup>. [2013]</li> </ul>
2	1.1.8	When working with children and young people with psychosis or
3		schizophrenia and their parents or carers:
4		make sure that discussions take place in settings in which
5		confidentiality, privacy and dignity are respected
6		<ul> <li>be clear with the child or young person and their parents or carers</li> </ul>
7		about limits of confidentiality (that is, which health and social care
8		professionals have access to information about their diagnosis and its
9		treatment and in what circumstances this may be shared with others) <sup>6</sup> .
10		[2013]
11	1.1.9	Discuss with young people with psychosis or schizophrenia of an
12		appropriate developmental level, emotional maturity and cognitive
13		capacity how they want their parents or carers to be involved in their care.
14		Such discussions should take place at intervals to take account of any
15		changes in circumstances, including developmental level, and should not
16		happen only once <sup>7</sup> . [2013]
17	1.1.10	Advise parents and carers about their right to a formal carer's assessment
18		of their own physical and mental health needs, and explain how to access
19		this <sup>8</sup> . <b>[2013]</b>
20	Commun	ication and information
21	1.1.11	Health and social care professionals working with children and young
22		people with psychosis or schizophrenia should be trained and skilled in:
23		<ul> <li>negotiating and working with parents and carers, and</li> </ul>
24		<ul> <li>managing issues relating to information sharing and confidentiality as</li> </ul>
25		these apply to children and young people. [2013]

<sup>&</sup>lt;sup>5</sup> Adapted from Service user experience in adult mental health (NICE guideline CG136).

<sup>6</sup> Adapted from Service user experience in adult mental health (NICE guideline CG136).

<sup>7</sup> Adapted from Service user experience in adult mental health (NICE guideline CG136).

<sup>8</sup> Adapted from Service user experience in adult mental health (NICE guideline CG136).

1 2 3	1.1.12	If a young person is 'Gillick competent' ask them what information can be shared before discussing their condition and treatment with their parents or carers. [2013]
4 5	1.1.13	When communicating with children and young people with psychosis or schizophrenia and their parents or carers:
6 7 8 9 10 11 12 13 14		<ul> <li>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</li> <li>use plain language where possible and clearly explain any clinical language</li> <li>check that the child or young person and their parents or carers understand what is being said</li> <li>use communication aids (such as pictures, symbols, large print, braille, different languages or sign language) if needed. [2013]</li> </ul>
16 17	1.1.14	Provide children and young people with psychosis or schizophrenia and their parents or carers, comprehensive written information about:
18 19 20 21 22 23		<ul> <li>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         'Information for the public' booklets</li> <li>support groups, such as third sector, including voluntary,         organisations<sup>9</sup>. [2013]</li> </ul>
24	1.1.15	Ensure that you are:
25 26 27 28		<ul> <li>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</li> <li>able to discuss and advise how to access these resources</li> </ul>

<sup>&</sup>lt;sup>9</sup> Adapted from <u>Service user experience in adult mental health</u> (NICE guideline CG136).

1 2		<ul> <li>able to discuss and actively support children and young people and their parents or carers to engage with these resources<sup>10</sup>. [2013]</li> </ul>
3 4 5	1.1.16	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>11</sup> . <b>[2013]</b>
6 7 8	1.1.17	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>12</sup> . <b>[2013]</b>
9	Culture, e	ethnicity and social inclusion
10	1.1.18	When working with children and young people with psychosis or
11		schizophrenia and their parents or carers:
12 13 14 15 16 17 18		<ul> <li>take into account that stigma and discrimination are often associated with using mental health services</li> <li>be respectful of and sensitive to children and young people's gender, sexual orientation, socioeconomic status, age, background (including cultural, ethnic and religious background) and any disability</li> <li>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>13</sup>. [2013]</li> </ul>
20 21	1.1.19	When working with children and young people and their parents or carers who have difficulties speaking or reading English:
22 23 24		<ul> <li>provide and work proficiently with interpreters if needed</li> <li>offer a list of local education providers who can provide English language teaching. [2013]</li> </ul>

Adapted from Service user experience in adult mental health (NICE guideline CG136).

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Adapted from Service user experience in adult mental health (NICE guideline CG136).

2 3	1.1.20	people with psychosis or schizophrenia and their parents or carers should have competence in:
4		assessment skills for people from diverse ethnic and cultural
5		backgrounds
6		using explanatory models of illness for people from diverse ethnic and
7		cultural backgrounds
8 9		<ul> <li>explaining the possible causes of psychosis and schizophrenia and treatment options</li> </ul>
10		addressing cultural and ethnic differences in treatment expectations
11		and adherence
12		addressing cultural and ethnic differences in beliefs regarding
13		biological, social and family influences on the possible causes of
14		mental health problems
15		<ul> <li>conflict management and conflict resolution<sup>14</sup>. [2013]</li> </ul>
16	1.1.21	Health and social care professionals inexperienced in working with
17		children and young people with psychosis or schizophrenia from diverse
18		ethnic and cultural backgrounds, and their parents or carers, should seek
19		advice and supervision from healthcare professionals who are
20		experienced in working transculturally <sup>15</sup> . <b>[2013]</b>
21	1.1.22	Local mental health services should work with primary care, other
22		secondary care and local third sector, including voluntary, organisations to
23		ensure that:
24		all children and young people with psychosis or schizophrenia have
25		equal access to services based on clinical need and irrespective of
26		gender, sexual orientation, socioeconomic status, age, background
27		(including cultural, ethnic and religious background) and any disability
28		<ul> <li>services are culturally appropriate<sup>16</sup>. [2013]</li> </ul>

<sup>14</sup> Adapted from Schizophrenia (NICE guideline CG82).
15 Adapted from Schizophrenia (NICE guideline CG82).
16 Adapted from Service user experience in adult mental health (NICE guideline CG136).

1.1.23 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>17</sup>. [2013]

### Transfer and discharge

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- 1.1.24 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 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>18</sup>. [2013]

# 1.2 Possible psychosis

# 23 Referral from primary care

1.2.1 When a child or young person experiences transient or attenuated 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 or over). [2013]

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<sup>&</sup>lt;sup>17</sup> Adapted from Schizophrenia (NICE guideline CG82).

<sup>&</sup>lt;sup>18</sup> Adapted from Service user experience in adult mental health (NICE guideline CG136).

I	Assessm	ent in specialist mental nealth services
2 3	1.2.2	Carry out an assessment of the child or young person with possible psychosis, ensuring that:
4 5 6 7 8 9		<ul> <li>assessments in CAMHS include a consultant psychiatrist</li> <li>assessments in early intervention in psychosis services are multidisciplinary</li> <li>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. [2013]</li> </ul>
11 12 13	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:
14 15 16		<ul> <li>the severity and frequency of symptoms</li> <li>the level of impairment and/or distress in the child or young person, and</li> <li>the degree of family disruption or concern. [2013]</li> </ul>
17 18 19	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. [2013]
20 21	Treatmer schizoph	nt options for symptoms not sufficient for a diagnosis of psychosis or renia
22 23 24	1.2.5	When transient or attenuated psychotic symptoms or other mental state changes associated with distress, impairment or help-seeking behaviour are not sufficient for a diagnosis of psychosis or schizophrenia:
25 26 27		<ul> <li>consider individual cognitive behavioural therapy (CBT) (delivered as set out in recommendation 1.3.29) with or without family intervention (delivered as set out in recommendation 1.3.28), and</li> </ul>

1 2 3		<ul> <li>offer treatments recommended in NICE guidance for children and young people with any of the anxiety disorders, depression, emerging personality disorder or substance misuse. [2013]</li> </ul>
4	1.2.6	Do not offer antipsychotic medication:
5 6 7		<ul> <li>for psychotic symptoms or mental state changes that are not sufficient for a diagnosis of psychosis or schizophrenia, or</li> <li>with the aim of decreasing the risk of psychosis. [2013]</li> </ul>
8	1.3	First episode psychosis
9	Referral f	rom primary care
10 11 12 13 14 15	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 specialist mental health service, either CAMHS (up to 17 years) or an early intervention in psychosis service (14 years or over), which includes a consultant psychiatrist with training in child and adolescent mental health.  [2013]
16 17 18 19	1.3.2	Antipsychotic medication in children and young people with a first presentation of sustained psychotic symptoms should not be started in primary care unless it is done in consultation with a consultant psychiatrist with training in child and adolescent mental health. [2013]
20		ent and care planning in secondary care
21	1.3.3	When carrying out an assessment:
222 223 224 225 226 227		<ul> <li>ensure there is enough time for:         <ul> <li>the child or young person and their parents or carers to describe and discuss their problems</li> <li>summarising the conclusions of the assessment and for discussion, with questions and answers</li> </ul> </li> <li>explain and give written material in an accessible format about any</li> </ul>
28		diagnosis given

1 2 3 4 5		<ul> <li>give information about different treatment options, including pharmacological and psychological interventions, and their benefits and side effects, to promote discussion and shared understanding</li> <li>offer support after the assessment, particularly if sensitive issues, such as childhood trauma, have been discussed<sup>19</sup>. [2013]</li> </ul>
6	1.3.4	Ensure that children and young people with first episode psychosis
7		receive a comprehensive multidisciplinary assessment. The assessment
8		should address the following domains:
9		<ul> <li>psychiatric (mental health problems, risk of harm to self or others,</li> </ul>
10		alcohol consumption and prescribed and non-prescribed drug history)
11		<ul> <li>medical, including medical history and full physical examination to</li> </ul>
12		identify physical illness (including organic brain disorders) and
13		prescribed drug treatments that may result in psychosis
14		<ul> <li>psychological and psychosocial, including social networks,</li> </ul>
15		relationships and history of trauma
16		<ul> <li>developmental (social, cognitive and motor development and skills,</li> </ul>
17		including coexisting neurodevelopmental conditions)
18		<ul> <li>physical health and wellbeing (including weight and height, and</li> </ul>
19		information about smoking, diet and exercise, and sexual health)
20		<ul> <li>social (accommodation, culture and ethnicity, leisure activities and</li> </ul>
21		recreation, carer responsibilities [for example, of parents or siblings])
22		<ul> <li>educational and occupational (attendance at school or college,</li> </ul>
23		educational attainment, employment and functional activity)
24		economic (family's economic status). [2013]
25	1.3.5	Doutingly monitor for other appyinting mental health problems, including
25 26	1.3.3	Routinely monitor for other coexisting mental health problems, including depression and anxiety, and substance misuse, particularly in the early
20 27		phases of treatment <sup>20</sup> . <b>[2013]</b>
_ ,		pridoco or troduniont . [2010]

Adapted from Service user experience in adult mental health (NICE guideline CG136).
 Adapted from Schizophrenia (NICE guideline CG82).

1 2 3	1.3.6	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:
4 5 6 7 8 9 10 11 12 13 14		<ul> <li>include activities that promote physical health and social inclusion, especially education, but also employment, volunteering and other occupations such as leisure activities</li> <li>provide support to help the child or young person and their parents or carers realise the plan</li> <li>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</li> <li>send a copy to the primary healthcare professional who made the referral<sup>21</sup>. [2013]</li> </ul>
15 16 17 18 19 20 21 22 23	1.3.7	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>22</sup> . <b>[2013]</b> 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:
24 25 26 27 28		<ul> <li>possible early warning signs of a crisis and coping strategies</li> <li>support available to help prevent hospitalisation</li> <li>where the child or young person would like to be admitted in the event of hospitalisation</li> <li>definitions of the roles of primary and secondary care professionals and</li> </ul>
29		the degree to which parents or carers are involved

Adapted from Service user experience in adult mental health (NICE guideline CG136).

Adapted from Service user experience in adult mental health (NICE guideline CG136).

1 2		<ul> <li>information about 24-hour access to services</li> <li>the names of key clinical contacts<sup>23</sup>. [2013]</li> </ul>
3 4 5 6 7	1.3.9	For children and young people with first episode psychosis who are unable to attend mainstream school or college, facilitate alternative educational input in line with their capacity to engage with educational activity and according to their individual needs, with an ultimate goal of returning to mainstream education, training or employment. [2013]
8 9 10	1.3.10	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>24</sup> . <b>[2013]</b>
11	Treatmen	at options for first episode psychosis
12	1.3.11	For children and young people with first episode psychosis offer:
13 14 15 16		<ul> <li>oral antipsychotic medication<sup>25</sup> (see recommendations 1.3.14–1.3.26) in conjunction with</li> <li>psychological interventions (family intervention with individual CBT, delivered as set out in recommendations 1.3.27–1.3.33). [2013]</li> </ul>
17 18 19 20 21 22 23 24	1.3.12	If the child or young person and their parents or carers wish to try psychological interventions (family intervention with individual CBT) alone without antipsychotic medication, advise that psychological interventions are more effective when delivered in conjunction with antipsychotic medication. If the child or young person and their parents or carers still wish to try psychological interventions alone, then offer family intervention with individual CBT. Agree a time limit (1 month or less) for reviewing treatment options, including introducing antipsychotic medication.
25		Continue to monitor symptoms, level of distress, impairment and level of

<sup>23</sup> Adapted from <u>Service user experience in adult mental health</u> (NICE guideline CG136).

Adapted from Service user experience in adult mental health (NICE guideline CG136). Adapted from <u>Get Vice door experience in adapt from the land in t</u> 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 <u>– guidance for doctors</u> for further information.

1		functioning, including educational engagement and achievement,
2		regularly. [2013]
3	1.3.13	If the child or young person shows symptoms and behaviour sufficient for
4		a diagnosis of an affective psychosis or disorder, including bipolar
5		disorder and unipolar psychotic depression, follow the recommendations
6		in Bipolar disorder: assessment and management (NICE
7		guideline CG185) or <u>Depression in children and young people:</u>
8		identification and management (NICE guideline CG28). [2013]
9	Choice o	f antipsychotic medication

## Choice of antipsychotic medication

- The choice of antipsychotic medication<sup>26</sup> should be made by the parents 10 1.3.14 or carers of younger children, or jointly with the young person and their 12 parents or carers, and healthcare professionals. Provide age-appropriate 13 information and discuss the likely benefits and possible side effects of 14 each drug including:
  - metabolic (including weight gain and diabetes)
- 16 extrapyramidal (including akathisia, dyskinesia and dystonia)
- cardiovascular (including prolonging the QT interval) 17
- hormonal (including increasing plasma prolactin) 18
  - other (including unpleasant subjective experiences). [2016]
- When choosing between olanzapine and other 'second generation' 20 1.3.15 antipsychotic medications<sup>27</sup>, discuss with the young person and their 21 22 parents or carers the possibility of greater weight gain with olanzapine.
- 23 Inform them that this effect is likely to happen soon after starting 24 treatment. [new 2016]

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<sup>&</sup>lt;sup>26</sup> At the time of consultation (January 2016), 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 <u>quidance for doctors</u> for further information.
 At the time of consultation (January 2016), 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 quidance for doctors for further information.

#### 1 How to use oral antipsychotic medication Before starting antipsychotic medication<sup>28</sup>, undertake and record the 2 1.3.16 following baseline investigations<sup>29</sup>: 3 4 weight and height (both plotted on a growth chart) 5 waist and hip circumference pulse and blood pressure 6 7 fasting blood glucose, glycosylated haemoglobin (HbA1c), blood lipid profile and prolactin levels 8 9 assessment of any movement disorders assessment of nutritional status, diet and level of physical activity. 10 11 [2013] 1.3.17 12 Before starting antipsychotic medication, offer the child or young person an electrocardiogram (ECG) if: 13 specified in the SPC for adults and/or children 14 a physical examination has identified specific cardiovascular risk (such 15 16 as diagnosis of high blood pressure) there is a personal history of cardiovascular disease 17 there is a family history of cardiovascular disease such as premature 18 19 sudden cardiac death or prolonged QT interval, or • the child or young person is being admitted as an inpatient<sup>30</sup>. [2013] 20 Treatment with antipsychotic medication<sup>31</sup> should be considered an 21 1.3.18 22 explicit individual therapeutic trial. Include the following:

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<sup>30</sup> Adapted from Schizophrenia (NICE guideline CG82).

<sup>&</sup>lt;sup>28</sup> At the time of publication (January 2013), 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 <u>Good practice in prescribing medicines – guidance for doctors</u> for further information.

<sup>&</sup>lt;sup>29</sup> See <u>Supplementary information</u> 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).

At the time of publication (January 2013), 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

1		<ul> <li>From a discussion with the child or young person and their parent or</li> </ul>
2		carer, record the side effects the child or young person is most and
3		least willing to tolerate.
4		Record the indications and expected benefits and risks of oral
5		antipsychotic medication, and the expected time for a change in
6		symptoms and appearance of side effects.
7		At the start of treatment give a dose below the lower end of the
8		licensed range for adults if the drug is not licensed for children and
9		young people and at the lower end of the licensed range if the drug is
10		licensed for children and young people; slowly titrate upwards within
11		the dose range given in the British national formulary (BNF), the British
12		national formulary for children (BNFC) or the SPC.
13		Justify and record reasons for dosages above the range given in the
14		BNF, BNFC or SPC.
15		Record the rationale for continuing, changing or stopping medication,
16		and the effects of such changes.
17		• Carry out a trial of the medication at optimum dosage for 4–6 weeks <sup>32</sup> .
18		[2013]
10	4 0 40	Marchen and the College College Control of the Control of the College Could be a section of the College Coul
19	1.3.19	Monitor and record the following regularly and systematically throughout
20		treatment, but especially during titration <sup>33</sup> :
21		efficacy, including changes in symptoms and behaviour
22		side effects of treatment, taking into account overlap between certain
23		side effects and clinical features of schizophrenia (for example, the
24		overlap between akathisia and agitation or anxiety)
25		the emergence of movement disorders
26		<ul> <li>weight, weekly for the first 6 weeks, then at 12 weeks and then every</li> </ul>
27		6 months (plotted on a growth chart)
28		<ul> <li>height every 6 months (plotted on a growth chart)</li> </ul>

obtained and documented. See the General Medical Council's Good practice in prescribing medicines

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 <sup>-</sup> guidance for doctors for further information.
 32Adapted from Schizophrenia (NICE clinical guideline CG82).
 33 See Supplementary information 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).

1		<ul> <li>waist and hip circumference every 6 months (plotted on a percentile</li> </ul>
2		chart)
3		<ul> <li>pulse and blood pressure (plotted on a percentile chart) at 12 weeks</li> </ul>
4		and then every 6 months
5		<ul> <li>fasting blood glucose, HbA1c, blood lipid and prolactin levels at</li> </ul>
6		12 weeks and then every 6 months
7		• adherence
8		physical health.
9		The secondary care team should maintain responsibility for monitoring
10		physical health and the effects of antipsychotic medication in children and
11		young people for at least the first 12 months or until their condition has
12		stabilised. Thereafter, the responsibility for this monitoring may be
13		transferred to primary care under shared care arrangements. [2013]
14	1.3.20	Discuss any non-prescribed therapies that children or young people, or
15		their parents or carers, wish to use (including complementary therapies)
16		with them. Discuss the safety and efficacy of the therapies, and possible
17		interference with the therapeutic effects of prescribed medication and
18		psychological interventions <sup>34</sup> . <b>[2013]</b>
19	1.3.21	Discuss the use of alcohol, tobacco, prescription and non-prescription
20		medication and illicit drugs with the child or young person, and their
21		parents or carers where this has been agreed. Discuss their possible
22		interference with the therapeutic effects of prescribed medication and
23		psychological interventions and the potential of illicit drugs to exacerbate
24		psychotic symptoms <sup>35</sup> . <b>[2013]</b>
25	1.3.22	'As required' (p.r.n.) prescriptions of antipsychotic medication should be
26		made as described in recommendation 1.3.18. Review clinical indications,
27		frequency of administration, therapeutic benefits and side effects at least

Adapted from <u>Schizophrenia</u> (NICE guideline CG82).
 Adapted from <u>Schizophrenia</u> (NICE guideline CG82).

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1		weekly. Check whether 'p.r.n.' prescriptions have led to a dosage above
2		the maximum specified in the BNF, BNFC or SPC <sup>36</sup> . <b>[2013]</b>
3	1.3.23	Do not use a loading dose of antipsychotic medication (often referred to
4		as 'rapid neuroleptisation') <sup>37</sup> . <b>[2013]</b>
5	1.3.24	Do not initiate regular combined antipsychotic medication, except for short
6		periods (for example, when changing medication) <sup>38</sup> . <b>[2013]</b>
7	1.3.25	If prescribing chlorpromazine, warn of its potential to cause skin
8		photosensitivity. Advise using sunscreen if necessary <sup>39</sup> . <b>[2013]</b>
9	1.3.26	Review antipsychotic medication annually, including observed benefits
10		and any side effects. [2013]
11	How to de	eliver psychological interventions
12	1.3.27	When delivering psychological interventions for children and young people
13		with psychosis or schizophrenia, take into account their developmental
14		level, emotional maturity and cognitive capacity, including any learning
15		disabilities, sight or hearing problems or delays in language development.
16		[2013]
17	1.3.28	Family intervention should:
18		include the child or young person with psychosis or schizophrenia if
19		practical
20		be carried out for between 3 months and 1 year
21		include at least 10 planned sessions
22		take account of the whole family's preference for either single-family
23		intervention or multi-family group intervention
24		take account of the relationship between the parent or carer and the
25		child or young person with psychosis or schizophrenia

36 Adapted from Schizophrenia (NICE guideline CG82).
37 Adapted from Schizophrenia (NICE guideline CG82).
38 Adapted from Schizophrenia (NICE guideline CG82).
39 Adapted from Schizophrenia (NICE guideline CG82).

1 2 3		<ul> <li>have a specific supportive, educational or treatment function and include negotiated problem solving or crisis management work<sup>40</sup>.</li> <li>[2013]</li> </ul>
4 5	1.3.29	CBT should be delivered on a one-to-one basis over at least 16 planned sessions (although longer may be needed) and:
6 7 8 9 10 11		<ul> <li>follow a treatment manual<sup>41</sup> so that:</li> <li>children and young people can establish links between their thoughts, feelings or actions and their current or past symptoms, and/or functioning</li> <li>the re-evaluation of the child or young person's perceptions, beliefs or reasoning relates to the target symptoms</li> <li>also include at least one of the following components:</li> </ul>
13 14 15 16 17 18 19		<ul> <li>normalising, leading to understanding and acceptability of their experience</li> <li>children and young people monitoring their own thoughts, feelings or behaviours with respect to their symptoms or recurrence of symptoms</li> <li>promoting alternative ways of coping with the target symptom</li> <li>reducing distress</li> <li>improving functioning<sup>42</sup>. [2013]</li> </ul>
21	Monitorin	ng and reviewing psychological interventions
22 23 24 25	1.3.30	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>43</sup> . <b>[2013]</b>

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Adapted from <u>Schizophrenia</u> (NICE guideline CG82).
 Treatment manuals that have evidence for their efficacy from clinical trials are preferred. If developed for adults, the approach should be adapted to suit the age and developmental level of the child or young person.

Adapted from Schizophrenia (NICE guideline CG82).

Adapted from Schizophrenia (NICE guideline CG82).

1 2 3	1.3.31	Healthcare teams working with children and young people with psychosis or schizophrenia should identify a lead healthcare professional within the team whose responsibility is to monitor and review:
4 5 6		<ul> <li>access to and engagement with psychological interventions</li> <li>decisions to offer psychological interventions and equality of access across different ethnic groups<sup>44</sup>. [2013]</li> </ul>
7	Compete	ncies for delivering psychological interventions
8	1.3.32	Healthcare professionals delivering psychological interventions should:
9 10 11 12		<ul> <li>have an appropriate level of competence in delivering the intervention to children and young people with psychosis or schizophrenia</li> <li>be regularly supervised during psychological therapy by a competent therapist and supervisor<sup>45</sup>. [2013]</li> </ul>
13 14 15 16	1.3.33	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>46</sup> . <b>[2013]</b>
17	1.4	Subsequent acute episodes of psychosis or schizophrenia
18 19	1.4.1	For children and young people with an acute exacerbation or recurrence of psychosis or schizophrenia offer:
20 21 22		<ul> <li>oral antipsychotic medication<sup>47</sup> in conjunction with</li> <li>psychological interventions (family intervention with individual CBT).</li> <li>[2013]</li> </ul>

Adapted from <u>Schizophrenia</u> (NICE guideline CG82).
 Adapted from <u>Schizophrenia</u> (NICE guideline CG82).

Adapted from Schizophrenia (NICE guideline CG82).

At the time of publication (January 2013), 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 <u>– guidance for doctors</u> for further information.

## Pharmacological interventions

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1.4.2 2 For children or young people with an acute exacerbation or recurrence of 3 psychosis or schizophrenia, offer oral antipsychotic medication or review existing medication<sup>48</sup>. The choice of drug should be influenced by the 4 5 same criteria recommended for starting treatment (see recommendations 6 1.3.14–1.3.26). Take into account the clinical response to and side effects associated with current and previous medication, and monitor as 7 described in recommendation 1.3.19<sup>49</sup>. [2013] 8 9 1.4.3 Aripiprazole is recommended as an option for the treatment of 10 schizophrenia in people aged 15 to 17 years who are intolerant of 11 risperidone, or for whom risperidone is contraindicated, or whose 12 schizophrenia has not been adequately controlled with risperidone. [This recommendation is from Aripiprazole for the treatment of schizophrenia in 13 people aged 15 to 17 years (NICE technology appraisal guidance 213).] 14 [2013] 15

## Psychological and psychosocial interventions

1.4.4 Offer family intervention (delivered as set out in recommendation 1.3.28) 17 to all families of children and young people with psychosis or 18 schizophrenia, particularly for preventing and reducing relapse. This can 19 20 be started either during the acute phase or later, including in inpatient settings<sup>50</sup>. [2013] 21 22 1.4.5 Offer CBT (delivered as set out in recommendation 1.3.29) to all children and young people with psychosis or schizophrenia, particularly for 23 symptom reduction. This can be started either during the acute phase or 24 later, including in inpatient settings<sup>51</sup>. [2013] 25

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<sup>&</sup>lt;sup>48</sup> At the time of publication (January 2013), 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 <u>Good practice in prescribing medicines</u> – <u>quidance for doctors</u> for further information.

<sup>&</sup>lt;sup>49</sup> Adapted from Schizophrenia (NICE guideline CG82).

Adapted from Schizophrenia (NICE guideline CG82).

<sup>&</sup>lt;sup>51</sup> Adapted from Schizophrenia (NICE guideline CG82).

1	1.4.6	Consider arts therapies (for example, dance movement, drama, music or
2		art therapy) for all children and young people with psychosis or
3		schizophrenia, particularly for the alleviation of negative symptoms. This
4		can be started either during the acute phase or later, including in inpatient
5		settings <sup>52</sup> . <b>[2013]</b>
6	1.4.7	If arts therapies are considered, they should be provided by Health
7		Professions Council (HPC) registered arts therapists, with experience of
8		working with children and young people with psychosis or schizophrenia.
9		The intervention should be provided in groups unless difficulties with
10		acceptability and access and engagement indicate otherwise. Arts
11		therapies should combine psychotherapeutic techniques with activity
12		aimed at promoting creative expression, which is often unstructured and
13		led by the child or young person. Aims of arts therapies should include:
14		<ul> <li>enabling children and young people with psychosis or schizophrenia to</li> </ul>
15		experience themselves differently and to develop new ways of relating
16		to others

- 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>53</sup>. **[2013]**
- 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 more efficacious psychological interventions, such as CBT, family intervention and arts therapies, are not available locally<sup>54</sup>. [2013]

<sup>54</sup> Adapted from Schizophrenia (NICE guideline CG82).

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Adapted from <u>Schizophrenia</u> (NICE guideline CG82).
 Adapted from <u>Schizophrenia</u> (NICE guideline CG82).

1 2	1.4.9	Do not offer adherence therapy (as a specific intervention) to children and young people with psychosis or schizophrenia <sup>55</sup> . <b>[2013]</b>
3 4	1.4.10	Do not routinely offer social skills training (as a specific intervention) to children and young people with psychosis or schizophrenia <sup>56</sup> . <b>[2013]</b>
5 6 7	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>57</sup> . <b>[2013]</b>
8	1.5	Referral in crisis and challenging behaviour
9 10 11	1.5.1	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>58</sup> . <b>[2013]</b>
12	1.5.2	To avoid admission, aim to:
13 14 15 16 17 18		<ul> <li>explore with the child or young person and their parents or carers what support systems they have, including other family members and friends</li> <li>support a child or young person in crisis and their parents or carers in their home environment</li> <li>make early plans to help the child or young person maintain their day-to-day activities, including education, work, voluntary work, and other occupations and leisure activities, wherever possible<sup>59</sup>. [2013]</li> </ul>
<ul><li>20</li><li>21</li></ul>	1.5.3	At the end of a crisis assessment, ensure that the decision to start home treatment depends not on the diagnosis, but on:
<ul><li>22</li><li>23</li><li>24</li><li>25</li></ul>		<ul> <li>the level of distress</li> <li>the severity of the problems</li> <li>the vulnerability of the child or young person and issues of safety and support at home</li> </ul>

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<sup>55</sup> Adapted from Schizophrenia (NICE guideline CG82).
56 Adapted from Schizophrenia (NICE guideline CG82).
57 Adapted from Schizophrenia (NICE guideline CG82).
58 Adapted from Service user experience in adult mental health (NICE guideline CG136).
59 Adapted from Service user experience in adult mental health (NICE guideline CG136).

1		• the child or young person's cooperation with treatment <sup>60</sup> . <b>[2013]</b>
2 3 4	1.5.4	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>61</sup> . <b>[2013]</b>
5 6 7 8	1.5.5	Follow the recommendations in <u>Self-harm in over 8s: short-term</u> management and prevention of recurrence (NICE guideline CG16) when managing acts of self-harm in children and young people with psychosis or schizophrenia who are 8 years or over <sup>62</sup> . <b>[2013]</b>
9	Hospital	care
10 11	1.5.6	If a child or young person needs hospital care, this should be in a setting appropriate to their age and developmental level. [2013]
12 13 14 15 16 17 18 19 20	1.5.7	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. [2013]  Give verbal and written information to children and young people with psychosis or schizophrenia admitted to hospital, and their parents or carers, about:
21 22 23 24 25 26 27		<ul> <li>the hospital and the ward in which the child or young person will stay</li> <li>treatments, activities and services available</li> <li>expected contact from health and social care professionals</li> <li>rules of the ward (including substance misuse policy)</li> <li>their rights, responsibilities and freedom to move around the ward and outside</li> <li>meal times</li> </ul>

Adapted from Service user experience in adult mental health (NICE guideline CG).

Adapted from Service user experience in adult mental health (NICE guideline CG136).

Adapted from Schizophrenia (NICE guideline CG82).

1		visiting arrangements.
2		Make sure there is enough time for the child or young person and their
3		parents or carers to ask questions <sup>63</sup> . <b>[2013]</b>
4	1.5.9	Undertake shared decision-making routinely with children or young people
5		in hospital who are of an appropriate developmental level, emotional
6		maturity and cognitive capacity, including, whenever possible, those who
7		are subject to the Mental Health Act (1983; amended 1995 and 2007).
8		Include their parents or carers if appropriate <sup>64</sup> . [2013]
9	1.5.10	Ensure that children and young people of compulsory school age have
10		access to a full educational programme while in hospital. The programme
11		should meet the National Curriculum, be matched to the child or young
12		person's developmental level and educational attainment, and should take
13		account of their illness and degree of impairment. [2013]
14	1.5.11	Ensure that children and young people in hospital continue to have
15		access to a wide range of meaningful and culturally appropriate
16		occupations and activities 7 days per week, and not restricted to 9am to
17		5pm. These should include creative and leisure activities, exercise, self-
18		care and community access activities (where appropriate). Activities
19		should be facilitated by appropriately trained educational, health or social
20		care professionals <sup>65</sup> . <b>[2013]</b>
21	1.5.12	Children and young people receiving community care before hospital
22		admission should be routinely visited while in hospital by the health and
23		social care professionals responsible for their community care <sup>66</sup> . <b>[2013]</b>
24	1.5.13	Promote good physical health, including healthy eating, exercise and
25		smoking cessation. [2013]

<sup>&</sup>lt;sup>63</sup> Adapted from Service user experience in adult mental health (NICE guideline CG136).

Adapted from Service user experience in adult mental health (NICE guideline CG136).

64 Adapted from Service user experience in adult mental health (NICE guideline CG136).

65 Adapted from Service user experience in adult mental health (NICE guideline CG136).

66 Adapted from Service user experience in adult mental health (NICE guideline CG136).

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# Rapid tranquillisation and restraint

2 3 4 5	1.5.14	Healthcare professionals undertaking rapid tranquillisation and/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. [2013]
6 7 8 9 10 11	1.5.15	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>67</sup> . <b>[2013]</b>
13 14	1.5.16	After rapid tranquillisation, offer the child or young person the opportunity to discuss their experiences. Provide them with a clear explanation of the
15		decision to use urgent sedation. Record this in their notes <sup>68</sup> . <b>[2013]</b>
<ul><li>15</li><li>16</li></ul>	1.6	decision to use urgent sedation. Record this in their notes <sup>68</sup> . [2013]  Early post-acute period
	<b>1.6</b> 1.6.1	
16 17 18		Early post-acute period  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
16 17 18 19 20 21	1.6.1	Early post-acute period  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. [2013]  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

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signs and symptoms of relapse for at least 2 years<sup>71</sup>. [2013]

<sup>67</sup> Adapted from Schizophrenia (NICE guideline CG82).
68 Adapted from Schizophrenia (NICE guideline CG82).
69 Adapted from Schizophrenia (NICE guideline CG82).
70 Adapted from Schizophrenia (NICE guideline CG82).

#### 1.7 Promoting recovery and providing possible future care in 1 primary care 2 1.7.1 Develop and use practice case registers to monitor the physical and 3 mental health of children and young people with psychosis or 4 schizophrenia in primary care<sup>72</sup>. [2013] 5 1.7.2 GPs and other primary healthcare professionals should monitor the 6 7 physical health of children and young people with psychosis or 8 schizophrenia at least once a year. They should bear in mind that people 9 with schizophrenia are at higher risk of cardiovascular disease than the general population. [2013] 10 11 1.7.3 Identify children and young people with psychosis or schizophrenia who smoke or who have high blood pressure, raised lipid levels or increased 12 waist measurement at the earliest opportunity and monitor for the 13 emergence of cardiovascular disease and diabetes. [2013] 14 1.7.4 15 Treat children and young people with psychosis or schizophrenia who 16 have diabetes and/or cardiovascular disease in primary care. Use the appropriate NICE guidance for children and young people where 17 available<sup>73</sup>,<sup>74</sup>. **[2013]** 18 19 1.7.5 Healthcare professionals in secondary care should ensure, as part of the 20 care programme approach (CPA) in England and care and treatment 21 plans in Wales, that children and young people with psychosis or 22 schizophrenia receive physical healthcare from primary care as described 23 in recommendations 1.7.2–1.7.4. Healthcare professionals in secondary 24 care should continue to maintain responsibility for monitoring and managing any side effects of antipsychotic medication<sup>75</sup>. [2013] 25

<sup>71</sup> Adapted from <u>Schizophrenia</u> (NICE guideline CG82).

<sup>5</sup> Adapted from Schizophrenia (NICE guideline CG82).

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<sup>72</sup> Adapted from Schizophrenia (NICE guideline CG82).
73 Adapted from Schizophrenia (NICE guideline CG82).

<sup>&</sup>lt;sup>74</sup> See <u>Diabetes (type 1 and type 2) in children and young people: diagnosis and management</u> (NICE guideline NG18).

1	1.7.6	When a child or young person with a diagnosis of psychosis or
2		schizophrenia presents with a suspected relapse (for example, with
3		increased psychotic symptoms or a significant increase in the use of
4		alcohol or other substances) and is still receiving treatment, primary
5		healthcare professionals should refer to the crisis section of the care plan.
6		Consider referral to the key clinician or care coordinator identified in the
7		crisis plan <sup>76</sup> . <b>[2013]</b>
8	1.7.7	For a child or young person with psychosis or schizophrenia being cared
9		for in primary care, consider referral to secondary care again if there is:
10		poor response to treatment
11		non-adherence to medication
12		• intolerable side effects from medication or the child or young person or
13		their parents or carers request a review of side effects
14		the child or young person or their parents or carers request
15		psychological interventions not available in primary care
16		comorbid substance misuse
17		• risk to self or others <sup>77</sup> . <b>[2013]</b>
18	1.8	Promoting recovery and providing possible future care in
19		secondary care
20	1.8.1	Children and young people with psychosis or schizophrenia who are being
21		treated in an early intervention in psychosis service should have access to
22		that service for up to 3 years (or until their 18th birthday, whichever is
23		longer) whatever the age of onset of psychosis or schizophrenia. [2013]
24	Psycholo	gical interventions
25	1.8.2	Offer family intervention to families of children and young people with
26		psychosis or schizophrenia to promote recovery. Deliver family

<sup>76</sup> Adapted from <u>Schizophrenia</u> (NICE guideline CG82).
<sup>77</sup> Adapted from <u>Schizophrenia</u> (NICE guideline CG82).
<sup>78</sup> Adapted from <u>Schizophrenia</u> (NICE guideline CG82).

1 1.8.3 Consider family intervention particularly for families of children and young 2 people with psychosis or schizophrenia who have: · recently relapsed or are at risk of relapse 3 persisting symptoms<sup>79</sup>. [2013] 4 5 1.8.4 Offer CBT to assist in promoting recovery in children and young people 6 with persisting positive and negative symptoms and for those in remission. Deliver CBT as described in recommendation 1.3.2980. [2013] 7 8 1.8.5 Consider arts therapies (see recommendation 1.4.7) to assist in promoting 9 recovery, particularly in children and young people with negative symptoms<sup>81</sup>. [2013] 10

## Pharmacological interventions

12	1.8.6	The choice of drug <sup>82</sup> should be influenced by the same criteria
13		recommended for starting treatment (see recommendations 1.3.14-
14		1.3.26) <sup>83</sup> . <b>[2013]</b>
1.5	4.0.7	D
15	1.8.7	Do not use targeted, intermittent dosage maintenance strategies <sup>84</sup>
16		routinely. However, consider them for children and young people with
17		psychosis or schizophrenia who are unwilling to accept a continuous
18		maintenance regimen or if there is another contraindication to
19		maintenance therapy, such as side-effect sensitivity <sup>85</sup> . [2013]

<sup>85</sup> Adapted from Schizophrenia (NICE guideline CG82).

<sup>&</sup>lt;sup>79</sup> Adapted from Schizophrenia (NICE guideline CG82).

<sup>&</sup>lt;sup>80</sup> Adapted from Schizophrenia (NICE guideline CG82). 81 Adapted from Schizophrenia (NICE guideline CG82).

At the time of publication (January 2013), 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.
 Adapted from Schizophrenia (NICE guideline CG82).

<sup>&</sup>lt;sup>84</sup> Defined as the use of antipsychotic medication only during periods of incipient relapse or symptom exacerbation rather than continuously.

#### 1 Interventions for children and young people whose illness has not responded 2 adequately to treatment 3 1.8.8 For children and young people with psychosis or schizophrenia whose 4 illness has not responded adequately to pharmacological or psychological 5 interventions: review the diagnosis 6 establish that there has been adherence to antipsychotic medication<sup>86</sup>. 7 8 prescribed at an adequate dose and for the correct duration 9 review engagement with and use of psychological interventions and ensure that these have been offered according to this guideline; if 10 11 family intervention has been undertaken 12 consider other causes of non-response, such as comorbid substance 13 misuse (including alcohol), the concurrent use of other prescribed medication or physical illness<sup>87</sup>. [2013] 14 Offer clozapine<sup>88</sup> to children and young people with schizophrenia whose 15 1.8.9 16 illness has not responded adequately to pharmacological treatment 17 despite the sequential use of adequate doses of at least two different antipsychotic drugs each used for 6-8 weeks<sup>89</sup>. [2013] 18 For children and young people whose illness has not responded 19 1.8.10 adequately to clozapine<sup>90</sup> at an optimised dose, consider a 20 multidisciplinary review, and recommendation 1.8.8 (including measuring 21 22 therapeutic drug levels) before adding a second antipsychotic to augment

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<sup>&</sup>lt;sup>86</sup> At the time of publication (January 2013), 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.

87 Adopted for a Color

Adapted from Schizophrenia (NICE guideline CG82).

<sup>88</sup> At the time of publication (January 2013), 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. Adapted from Schizophrenia (NICE clinical guideline 82).

<sup>90</sup> At the time of publication (January 2013), 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.

1 treatment with clozapine. An adequate trial of such an augmentation may 2 need to be up to 8–10 weeks. Choose a drug that does not compound the common side effects of clozapine<sup>91</sup>. [2013] 3

#### Education, employment and occupational activities for children and young 4

#### 5 people with psychosis and schizophrenia

3	people with psychosis and schizophreina				
6	1.8.11	For children and young people of compulsory school age, liaise with the			
7		child or young person's school and educational authority, subject to			
8		consent, to ensure that ongoing education is provided. [2013]			
9	1.8.12	Liaise with the child or young person's school and with their parents or			
10		carers, subject to consent, to determine whether a special educational			
11		needs assessment is necessary. If it is agreed that this is needed, explain			
12		to parents or carers how to apply for an assessment and offer support			
13		throughout the process. [2013]			
14	1.8.13	Provide supported employment programmes for those young people with			
15		psychosis or schizophrenia above compulsory school age who wish to			
16		return to work or find employment. Consider other work-related activities			
17		and programmes when individuals are unable to work or are unsuccessful			
18		in their attempts to find employment <sup>92</sup> . <b>[2013]</b>			
19	1.8.14	Mental health services should work in partnership with local stakeholders,			
20		including those representing black and minority ethnic groups, to enable			
21		young people with psychosis or schizophrenia to access local			
22		employment and educational opportunities. This should be sensitive to the			
23		young person's needs and skill level and is likely to involve working with			
24		agencies such as Jobcentre Plus, disability employment advisers and			
25		non-statutory providers <sup>93</sup> . <b>[2013]</b>			

93 Adapted from Schizophrenia (NICE guideline CG82).

<sup>&</sup>lt;sup>91</sup> Adapted from Schizophrenia (NICE guideline CG82).
<sup>92</sup> Adapted from Schizophrenia (NICE guideline CG82).
<sup>93</sup> Adapted from (NICE guideline CG82).

1.8.15	Routinely record the daytime activities of children and young people with
	psychosis or schizophrenia in their care plans, including educational and
	occupational outcomes <sup>94</sup> . <b>[2013]</b>

# Context

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- This guideline is concerned with the recognition and management of psychosis and schizophrenia in children and young people up to the age of 18. The term 'psychosis' is used in this guideline to refer to the group of psychotic disorders that includes schizophrenia, schizoaffective disorder, schizophreniform disorder and delusional disorder. This guideline also addresses those children and young people considered
- clinically to be at high risk or prodromal for psychosis and schizophrenia. The
- 11 recognition, treatment and management of affective psychoses (such as bipolar
- disorder or unipolar psychotic depression) are covered by other NICE guidelines.
- 13 Psychosis and the specific diagnosis of schizophrenia in children and young people
- represent a major psychiatric disorder, or cluster of disorders that alters a person's
- perception, thoughts, mood and behaviour. The symptoms of psychosis are usually
- divided into 'positive symptoms', 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
- 19 withdrawal and self-neglect). Children and young people who develop psychosis will
- 20 have their own unique combination of symptoms and experiences, the precise
- 21 pattern of which will be influenced by their circumstances and stage of development.
- 22 Psychosis and schizophrenia are commonly preceded by a so-called prodromal
- period, lasting up to 12 months, in which the child or young person's behaviour and
- 24 experience are altered. Relatives may become aware of these changes first.
- 25 Changes include the emergence of transient and/or attenuated psychotic symptoms,
- such as hallucinations and/or delusions with associated impaired functioning. More
- subtly, the child or young person may become socially withdrawn or suspicious, with
- 28 alterations in expressed feeling. It is important to note that most children and young
- 29 people with transient or attenuated psychotic symptoms do not go on to develop
- 30 psychosis or schizophrenia, although those with such symptoms do appear to be at

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<sup>&</sup>lt;sup>94</sup> Adapted from <u>Schizophrenia</u> (NICE guideline CG82).

- 1 higher risk than other children and young people of developing psychosis and
- 2 schizophrenia up to 10 years after onset of symptoms.
- 3 The prevalence of psychotic disorders in children aged between 5 and 18 years has
- 4 been estimated to be 0.4% (the figure across all ages and populations in the UK is
- 5 0.7%). Schizophrenia accounts for 24.5% of all psychiatric admissions in young
- 6 people aged 10–18 years (the overall admission rate is 0.46 per 1000 for this age
- 7 range), with an exponential rise across the adolescent years. The rise in incidence
- 8 increases most from age 15 onwards.
- 9 There is a worse prognosis for psychosis and schizophrenia when onset is in
- 10 childhood or adolescence. The symptoms and experience of psychosis and
- schizophrenia are often distressing and the effects of the illness are pervasive.
- 12 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
- 14 needs intensive social and psychiatric support. Psychosis and 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
- 17 parents and carers.
- 18 Although the mainstay of treatment for psychosis and 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
- 21 sensitive than adults to the potential adverse effects of antipsychotics, including
- 22 weight gain, metabolic effects and movement disorders. A number of psychological
- 23 interventions, including family intervention, cognitive behavioural therapy (CBT) and
- 24 arts therapies, have been used but evidence of efficacy is currently unavailable in
- children and young people and provision of these therapies for children and young
- 26 people and for adults is variable.
- 27 This guideline covers the care provided by primary, community, secondary, tertiary
- and other health and social care professionals who have direct contact with, and
- 29 make decisions concerning, the care of children and young people with psychosis or
- 30 schizophrenia, including child and adolescent mental health services (CAMHS) and
- 31 early intervention in psychosis services.

- 1 Early intervention in psychosis services provide people aged 14–35 years with a
- 2 more intensive therapeutic service than traditional community services. They are
- designed to intervene early, and deliver support and evidence-based interventions in
- 4 a 'normalising' environment for the first 3 years after onset of psychosis.
- 5 There is geographical variation in the configuration and integration of CAMHS and
- 6 early intervention in psychosis services, and in the provision and integration of other
- 7 services for children and young people with psychosis and schizophrenia, including
- 8 education, employment and rehabilitation, and social services. In particular, provision
- 9 for the needs of 16- and 17-year-olds with psychosis and schizophrenia can be
- 10 fragmented and inadequate and they can experience difficulties in gaining access to
- appropriate accommodation and vocational or occupational support and
- 12 rehabilitation.
- 13 A number of recommendations in this guideline have been adapted from
- recommendations in other NICE clinical guidelines. Where this occurred, the
- 15 guideline committee was careful to preserve the meaning and intent of the original
- recommendation. Changes to wording or structure were made in order to fit the
- 17 recommendations into this guideline. In all cases, the original source of any adapted
- 18 recommendation is indicated in a footnote.
- 19 The guideline incorporates Aripiprazole for the treatment of schizophrenia in people
- 20 aged 15 to 17 years (NICE technology appraisal guidance 213).

## 21 **More information**

To find out what NICE has said on topics related to this guideline, see our web page on psychosis and schizophrenia.

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## Recommendations for research

- 24 In 2013 the guideline committee made the following recommendations for research.
- 25 1 What are the long-term outcomes, both psychotic and non-
- psychotic, for children and young people with attenuated or

1	transient psychotic symptoms suggestive of a developing
2	psychosis, and can the criteria for 'at risk states' be refined to
3	better predict those who will and those who will not go on to
4	develop psychosis?
5	The suggested programme of research would be in two phases. First, a systematic
6	review and meta-analysis of prospective observational studies/cohorts of children
7	and young people identified at high or ultra-high risk of developing psychosis would
8	be undertaken. The review would identify risk and protective factors most strongly
9	associated with the later development of psychotic and non-psychotic outcomes.
10	Second, the factors identified in the first phase would be used to identify a large
11	cohort of children and young people with these factors and to evaluate the
12	effectiveness of these refined criteria for predicting the later development of
13	psychotic and non-psychotic outcomes.
14	Why this is important
15	A major problem with trials of treatments for populations of children and young
16	people deemed to be 'at risk' or 'at ultra-high risk' of developing psychosis is
17	identifying the precise symptoms and/or behaviours or (risk) factors that are most
18	strongly associated with the development of psychosis; and conversely, which
19	(protective) factors are likely to be associated with a lowered risk of later psychosis.
20	At present, identified factors have a low predictive value, with only about 10-20% of
21	children and young people who have been identified as at high risk going on to
22	develop psychosis. If these risk and protective factors could be refined, it would be
23	possible to better target children and young people who are most at risk, and reduce
24	the numbers of those thought to be 'at risk' who do not go on to later develop
25	psychosis.
26	2 What is the clinical and cost effectiveness of omega-3 fatty acids
27	in the treatment of children and young people considered to be at
28	high risk of developing psychosis?
29	The suggested programme of research would need to test out, using an adequately
30	powered, multicentre randomised controlled design, the likely benefits and costs of
31	using omega-3 fatty acids for children and young people at high risk of developing

1	psychosis. The outcomes considered should include transition to psychosis, quality
2	of life, symptomatic and functional improvements, treatment acceptability, side
3	effects and self-harm. There should be follow-up at 3 years. The trial should also
4	estimate the cost effectiveness of intervening.
5	Why this is important
6	A number of interventions have been trialled in an attempt to avert the development
7	of psychosis, including drugs, psychological interventions and other interventions. A
8	relatively recent, moderate-sized randomised controlled trial of omega-3 fatty acids
9	has shown the best evidence of any intervention, to date, reducing the rates of
10	transition from 'high risk' states to a sustained psychosis. However, this is a single
11	trial, which is underpowered, undertaken in one centre and lacks any health
12	economic analysis.
13	3 What is the clinical and cost effectiveness for family intervention
14	combined with individual CBT in the treatment of children and
15	young people considered to be at high risk of developing
16	psychosis and their parents or carers?
17	The suggested programme of research would need to test out, using an adequately
18	powered, multicentre, randomised controlled design, the likely benefits and costs of
19	providing family intervention, combined with individual CBT, for children and young
20	people at high risk of developing psychosis and their parents or carers. The
21	outcomes considered should include transition to psychosis, quality of life,
22	symptomatic and functional improvements, treatment acceptability and self-harm.
23	There should be follow-up at 3 years. The trial should also estimate the cost
24	effectiveness of intervening.
25	Why this is important
26	A number of interventions have been trialled in an attempt to avert the development
27	of psychosis, including drugs, psychological interventions and other interventions.
28	After the first episode of psychosis, family intervention as an adjunct to antipsychotic
29	medication substantially and significantly reduces relapse rates. A single small trial

1	combining CBT family treatment with individual CBT without antipsychotic treatment
2	suggested an important reduction in transition rates to the first psychosis.
3	4 What is the clinical and cost effectiveness of psychological
4	intervention alone, compared with antipsychotic medication and
5	compared with psychological intervention and antipsychotic
6	medication combined, in young people with first episode
7	psychosis?
8	The programme of research would compare the clinical and cost effectiveness of
9	psychological intervention alone, compared with antipsychotic medication, and
10	compared with psychological intervention and antipsychotic medication combined,
11	for young people in the early stages of psychosis using an adequately powered
12	study with a randomised controlled design. The combination of psychological
13	interventions most likely to have an impact is family intervention and individual CBT.
14	The key outcomes should include symptoms, relapse rates, quality of life, treatment
15	acceptability, experience of care, level of psychosocial functioning and the cost
16	effectiveness of the interventions.
17	Why this is important
18	The personal and financial cost of psychosis and schizophrenia to the person, their
19	family and friends, and to society is considerable. The personal cost is reflected in a
20	suicide rate of nearly 15% among people with schizophrenia, a lifelong
21	unemployment rate that varies between 50 and 75%, depending on geographical
22	location, and reduced life expectancy. The additional cost to the healthcare system
23	for one person with schizophrenia is estimated to reach over £50,000 per year, on
24	average, throughout their life.
25	Currently, the mainstay of treatment is antipsychotic medication, but the potential
26	adverse effects are such that there is considerable impetus to develop alternative
27	treatment strategies to allow either lower doses or to remove the need for medication
28	entirely. It has been recognised that psychological interventions as an adjunct to
29	antipsychotic medication have an important part to play in the treatment of
30	schizophrenia. NICE clinical guideline 82 identified family intervention and CBT as
31	adjunct treatments and current evidence suggests that these interventions are cost

1	saving. However, evidence for adjunctive family intervention and CBT is lacking in
2	children and young people with psychosis. Furthermore, there has been one recent
3	positive trial of CBT as a first-line treatment, without antipsychotics, for young people
4	in the early stages of psychosis.
5	5 What is the clinical effectiveness of clozapine for children and
6	young people with schizophrenia with symptoms unresponsive to
7	antipsychotic medication and psychological treatment combined?
8	The suggested programme of research would need to test out, using an adequately
9	powered, randomised controlled design, the likely benefits of using clozapine,
10	compared with another antipsychotic, for children and young people with symptoms
11	of schizophrenia unresponsive to antipsychotic medication and psychological
12	treatment combined. The outcomes considered should include quality of life,
13	symptomatic and functional improvements, treatment acceptability, side effects and
14	length of hospitalisation.
15	Why this is important
16	Currently, about 30% of people with schizophrenia have symptoms that do not
17	respond adequately to treatment with an antipsychotic. Although precise figures are
18	unavailable, especially for children and young people, smaller percentages of people
19	do not respond when a second, alternative, antipsychotic and an adequate course of
20	psychological treatment have been tried. For these people, clozapine, which has a
21	different dopamine receptor subtype blocking profile from other antipsychotics, has
22	become an important treatment option in adults. However, evidence is lacking (only
23	one study) about the effectiveness of clozapine for 'treatment-resistant
24	schizophrenia' in children and young people.
25	6 What is the most effective management strategy for preventing
26	the development of excessive weight gain and metabolic syndrome
27	associated with the use of antipsychotic medication in children and
28	young people?
29	The suggested programme of research would be in two parts: (1) a longitudinal

cohort study (a national observational database of at least 12 months' duration) to

- determine the incidence and predictors of adverse physical effects of antipsychotic
- 2 medication; (2) a randomised controlled trial of behavioural and/or medical
- 3 approaches to reduce weight gain and the risk of metabolic syndrome associated
- 4 with antipsychotic medication.

## Why this is important

- 6 Rapid weight gain associated with antipsychotic medication and poor physical health
- 7 (smoking, lack of exercise) leading to type 2 diabetes and metabolic syndrome are
- 8 major sources of morbidity and premature mortality in young people with psychosis
- and schizophrenia. Most evidence of adverse effects comes from short-term studies
- of antipsychotics (maximum 8–12 weeks). In contrast, very little is known about the
- longer term adverse effects of these drugs. Evidence is needed both on longer term
- adverse effects as well as on effective early intervention strategies that reduce these
- risk factors and improve physical health outcomes.

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# Supplementary information on baseline investigations and

# monitoring

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Table 1 Baseline investigations and monitoring for 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 <sup>1</sup> (plotted on a growth chart)	Yes	Yes	Yes	Yes	
Height <sup>1</sup> (plotted on a growth chart)	Yes			Yes	
Waist and hip circumference (plotted on a percentile chart)	Yes			Yes	
Pulse	Yes		Yes	Yes	
Blood pressure (plotted on a percentile chart)	Yes		Yes	Yes	
Fasting blood glucose	Yes		Yes	Yes	
HbA <sub>1c</sub> (glycosylated haemoglobin)	Yes		Yes	Yes	
Blood lipid profile	Yes		Yes	Yes	
Prolactin level	Yes		Yes	Yes	
Movement disorders (extrapyramidal symptoms, akathisia, dystonia and tardive dyskinesia)	Yes				Yes <sup>2</sup>
Nutritional status, diet and level of physical activity	Yes				Yes
The side effects the child or young person is most or least willing to tolerate	Yes				
ECG	Yes <sup>3</sup>				
Efficacy					Yes
Side effects					Yes
Adherence					Yes

<sup>&</sup>lt;sup>1</sup> Calculate and document BMI (percentile).

<sup>&</sup>lt;sup>2</sup> Even if no baseline assessment (and at each clinic visit if more frequent).

<sup>&</sup>lt;sup>3</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.

# Update information

- 2 This guideline is an update of NICE guideline CG155 (published January 2013
- 3 A new recommendation has been added on providing information about olanzapine
- 4 when choosing antipsychotic medication for children and young people with a first
- 5 episode of psychosis. This is marked as **[new 2016]**. The evidence has been
- 6 reviewed and no change made to the recommended action in 1 recommendation on
- 7 choosing antipsychotic medication for children and young people with a first episode
- 8 of psychosis. This is marked as [2016].
- 9 Where recommendations are shaded in grey and end [2013], the evidence has not
- 10 been reviewed since the original guideline.
- 11 See also the <u>original NICE guideline and supporting documents</u>.
- 12 Changes after publication
- 13 May 2013: minor modification.
- 14 **ISBN**: