Guidelines

Recognition and management of psychosis and schizophrenia in children and young people: summary of NICE guidance

Tim Kendall,1 2 3 Chris Hollis,4 Megan Stafford,1 Clare Taylor,1 On behalf of the Guideline Development Group

Psychosis, including schizophrenia, comprises a major group of psychiatric disorders characterised by hallucinations and/or delusions (psychotic symptoms) that alter perception, thoughts, affect, and behaviour, and which can considerably impair a child or young person’s development, relationships, and physical health. Schizophrenia is estimated to affect 1.6 to 1.9 per 100 000 in the child population,1 2 with prevalence increasing rapidly from age 14.3 Psychosis and schizophrenia in children (age 12 years and under) and young people (up to age 17 years) are leading causes of disability and are more severe and have worse prognosis than if onset is in adulthood, owing to disruption to social and cognitive development. Young people with schizophrenia tend to have a shorter life expectancy than the general population, largely because of suicide, injury, or cardiovascular disease,4 the last partly from antipsychotic medication. Children and young people with transient or attenuated psychotic symptoms are at increased risk of developing psychosis or schizophrenia,5 and delayed treatment can impair longer term outcomes,6 making early recognition and intervention crucial.

This article summarises the most recent recommendations from the National Institute for Health and Clinical Excellence (NICE) guideline on psychosis and schizophrenia in children and young people.4

Recommendations

NICE recommendations are based on systematic reviews of the best available evidence and explicit consideration of cost effectiveness. When minimal evidence is available, recommendations are based on the Guideline Development Group’s experience and opinion of what constitutes good practice. Evidence levels for the recommendations are given in italic in square brackets.

General principles of care

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. [Based on the experience and opinion of the Guideline Development Group (GDG)]

Referral from primary care for possible psychosis

When a child or young person experiences transient or attenuated psychotic symptoms (such as possible or fleeting hallucinations or delusions) or other experiences suggestive of possible psychosis, refer for assessment without delay to a specialist mental health service such as child and adolescent mental health services or an early intervention in psychosis service (14 years or over). [Based on the experience and opinion of the GDG]

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

When transient or attenuated psychotic symptoms or other mental state changes associated with distress, sustained impairment in functioning, or help seeking behaviour by the child or young person (or their parent or carer) are not sufficient for a diagnosis of psychosis or schizophrenia:5–10:

- Consider individual cognitive behavioural therapy with or without family intervention, and
- Offer treatments recommended in NICE guidance for those with any of the anxiety disorders,11 12 depression,13 emerging personality disorder,14 15 or substance misuse.16–20 [Based on moderate to low quality evidence from randomised controlled trials in children and young people and on the experience and opinion of the GDG]

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. [Based on very low quality evidence from randomised controlled trials and an economic model in children and young people]

Referral from primary care for first episode psychosis

Urgently refer all those with a first presentation of sustained psychotic symptoms (lasting four weeks or more) to a specialist mental health service, either to child and adolescent mental health services (age ≤17 years) or to an early intervention in psychosis service (≥14 years). Both services should include among their staff a consultant psychiatrist with training in child and adolescent mental health. [Based on the experience and opinion of the GDG]

Assessment of first episode

Ensure that those with first episode psychosis receive a comprehensive multidisciplinary assessment, examining the following domains:

- Psychiatric (mental health problems, risk of harm to self or others, alcohol consumption, and history of prescribed and non-prescribed drugs)
- Medical, including medical history and full physical examination to identify physical illness (including organic brain disorders) and prescribed drug treatments that may result in psychosis
Treatment options for first episode psychosis

Offer oral antipsychotic medication in conjunction with psychological interventions (family intervention with individual cognitive behavioural therapy). [Based on high quality evidence from randomised controlled trials conducted in adults and an economic model using adult data from NICE’s adult schizophrenia guideline and on the experience and opinion of the GDG]

If the child or young person and their parents or carers wish to try psychological interventions (family intervention with individual cognitive behavioural therapy) 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 cognitive behavioural therapy. Agree a time limit (one month or less) for reviewing treatment options, including introducing antipsychotic medication. Continue to regularly monitor symptoms, level of distress, impairment, and level of functioning, including educational engagement and achievement. [Based on high quality evidence from randomised controlled trials conducted in adults and an economic model using adult data from NICE’s adult schizophrenia guideline and on the experience and opinion of the GDG]

Choice of antipsychotic medication

This choice 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 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).

[Based on low to very low quality evidence from randomised controlled trials and observational studies conducted in children and young people; on high quality evidence from randomised controlled trials conducted in adults from NICE’s adult schizophrenia guideline, and on the experience and opinion of the GDG]

How to use oral antipsychotic medication

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, glycated haemoglobin (HbA1c), blood lipid profile, and prolactin levels
- Assessment of any movement disorders
- Assessment of nutritional status, diet, and level of physical activity.

[Based on low to very low quality evidence from randomised controlled trials and observational studies conducted in children and young people; on high quality evidence from randomised controlled trials conducted in adults from NICE’s adult schizophrenia guideline, and on the experience and opinion of the GDG]

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 six weeks, then at 12 weeks, and then every six months (plotted on a growth chart)
- Height every six months (plotted on a growth chart)
- Waist and hip circumference every six months (plotted on a centile chart)
- Pulse and blood pressure (plotted on a centile chart) at 12 weeks and then every six months
- Fasting blood glucose, HbA1c, blood lipids, and prolactin levels at 12 weeks and then every six months
- Adherence
- Physical health.

The secondary care team should maintain responsibility for monitoring physical health and the effects of antipsychotic medication for at least the first 12 months or until the condition has stabilised. Therafter, the responsibility for this monitoring may be transferred to primary care under shared care arrangements. [Based on the experience and opinion of the GDG, which was informed by low to very low quality evidence from randomised controlled trials and observational studies conducted in children and young people and on high quality evidence from randomised controlled trials conducted in adults from NICE’s adult schizophrenia guideline]

How to deliver psychological interventions

When delivering psychological interventions 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. [Based on the experience and opinion of the GDG]

Family intervention should:

- Include the child or young person, if practical
- Be carried out for between three months and one 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
FURTHER INFORMATION ON THE GUIDANCE

Several areas of inconsistent practice prompted the development of this guideline. The guideline is clear that children and young people, who are at high risk but do not meet criteria for diagnosis of a psychotic disorder, should not be offered antipsychotic medication with the aim of preventing transition to psychosis. This recommendation aims to reduce the potential adverse effects of exposure to antipsychotic medication where there is no established benefit. Interventions for this group should be targeted at reducing distress (including family intervention, individual cognitive behavioural therapy, and other evidence-based treatments for coexisting conditions, such as anxiety, depression, and substance misuse). Provision of access to interventions, especially family intervention and cognitive behavioural therapy, may also be inconsistent. For most parts of England and Wales provision is usually poor. It is hoped that the children and young people’s project “Improving Access to Psychological Therapies (IAPT)” — which aims to provide more psychological therapists to deliver interventions for children and young people in the English NHS — will go some way to alleviating this shortfall. But for this to be achieved, IAPT therapists would have to be fully integrated into the CAMHS multidisciplinary teams and would require specific training in cognitive behavioural therapy for psychosis and schizophrenia.

In addition, children and young people with psychosis and schizophrenia have inconsistent access to education and employment, which the guideline seeks to improve, and services vary considerably in their provision of help with either of these.

There is considerable variation in prescribing of antipsychotic drugs in children and young people and also in monitoring and physical examination in relation to risk of rapid weight gain and metabolic syndrome. The guideline provides clear recommendations on the physical monitoring of antipsychotic medication and advises establishing shared care arrangements with primary care to resolve problems with prescribing and physical monitoring. Integration between mental health and social services is highly variable, which is especially problematic for this group of children and young people, for whom opportunities for social integration, employment, and access to disability allowance, unemployment benefits, and other financial supports can be crucial to developing any form of independence.

Methods

This guideline was developed by the National Collaborating Centre for Mental Health using NICE guideline methods (http://publications.nice.org.uk/the-guidelines-manual-pmg6). A multidisciplinary team of healthcare professionals from psychiatry, psychology, paediatrics, general practice, and nursing and service user and carer representatives was established as the Guideline Development Group (GDG) to review the evidence and develop the subsequent recommendations. The guideline then went through an external consultation with stakeholders. The GDG considered the stakeholders’ comments, re-analysed the data where necessary, and modified the guideline as appropriate.

NICE has produced three different versions of the guideline: a full version; a summary version known as the “NICE guideline”; and a version for children and young people with psychosis and schizophrenia, their parents and carers, and the public (see NICE website).

Areas for future research

- The long term outcomes for children and young people with attenuated or transient psychotic symptoms suggestive of a developing psychosis
- 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
  - Family intervention combined with individual cognitive behavioural therapy in the treatment of children and young people considered to be at high risk of developing psychosis, and their parents or carers
  - Psychological intervention alone, compared with antipsychotic medication alone and with psychological intervention and antipsychotic medication combined, in young people with first episode psychosis
- The clinical effectiveness of clozapine for children and young people with schizophrenia with symptoms unresponsive to antipsychotic medication and psychological treatment combined
- The most effective management strategy to prevent the development of excessive weight gain and metabolic syndrome associated with the use of antipsychotic medication in children and young people

- Promoting alternative ways of coping with the target symptom
- Reducing distress
- Improving functioning.

[Based on the experience and opinion of the GDG, which was informed by high quality evidence from randomised controlled trials conducted in adults from NICE’s adult schizophrenia guideline]

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

- Take account of the relationship between the parent or carer and the child or young person
- Have a specific supportive, educational, or treatment function and include negotiated problem solving or crisis management work.
- Follow a treatment manual (adapting the approach to suit the age and developmental level of the child or young person) so that:
  - They can establish links between their thoughts, feelings, or actions and their current or past symptoms, and/or functioning
  - The re-evaluation of their 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
  - Monitoring their own thoughts, feelings, or behaviours with respect to their symptoms or recurrence of symptoms

Treatment of subsequent acute exacerbation or recurrence of psychosis or schizophrenia

Offer oral antipsychotic medication in conjunction with psychological interventions (family intervention with individual cognitive behavioural therapy). [Based on high quality evidence from randomised controlled trials conducted with adults and an economic model using adult data and on the experience and opinion of the GDG]

Offer family intervention to all families of children and young people with psychosis or schizophrenia, particularly for preventing and reducing relapse. Start this either during the acute phase or later, including in inpatient settings. [Based on high quality evidence from randomised controlled trials conducted in adults from NICE’s adult schizophrenia guideline and on the experience and opinions of the GDG]
Hospital care
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 in the community wherever possible. If hospital admission is unavoidable, provide support for parents or carers when the child or young person is admitted. [Based on the experience and opinions of the GDG, which were informed by the discussions of the topic group]

Physical healthcare
General practitioners and other primary healthcare professionals should monitor the physical health of children and young people with psychosis or schizophrenia at least once a year, bearing in mind that people with schizophrenia are at higher risk of cardiovascular disease than the general population. [Based on the experience and opinions of the GDG]

Education, employment, and occupational activities
For children and young people of compulsory school age, liaise with their school and education authority, subject to consent, to ensure that ongoing education is provided. [Based on the experience and opinions of the GDG]

Overcoming barriers
Assessment and diagnosis of psychosis and schizophrenia in children and young people can be challenging because it has to take into account developmental factors and potential differential diagnoses and comorbid conditions, which differ from those in adults. The NICE guideline aims to reduce delayed recognition and increase accurate diagnosis and early uptake of evidence based treatments by supporting rapid referral of children and young people with suspected psychosis from primary care to a consultant psychiatrist with training in child and adolescent mental health (through either child and adolescent mental health services (CAMHS) or an early intervention in psychosis service). Ideally, trained staff in CAMHS should be embedded in the early intervention in psychosis service and take the lead for assessment and management of young people aged 14 and 17 years. The guideline advises that young people who enter early intervention in psychosis services at age 14 should receive follow-up from this service beyond the usual three year period to facilitate a smooth transition to adult mental health services.

The members of the Guideline Development Group were Chris Hollis (chair), Tim Kendall (facilitator), Megan Stafford (systematic reviewer), Henna Bhatti, Max Birchwood, Rory Byrne, Melissa Chan, Nadir Cheema, Andrew Clark, Jaeta Ego, Elena Garvalda, Laura Graham, Marie Halton, Hannah Jackson, Anthony James, Linneã Larsson, Christina Loucas, Tim McDougall, Anthony Morrison, Gilian Rose, Kate Satrettin, David Shiers, Kirsty Smedley, Sarah Stockton, Clare Taylor, Danyl Thompson, and David Ward.

Contributors: All authors contributed to the conception and drafting of this article and revising it critically. They have all approved this version. TK is the guarantor.

Contributors: All authors have completed the Unified Competing Interest form at www.cmj.org/col_disclosure.pdf (available on request from the corresponding author) and declare: TK, MS, and CT had support from the National Collaborating Centre for Mental Health for the submitted work. TK receives funding from NICE to support guideline development work at the National Collaborating Centre for Mental Health; no other relationships or activities that could appear to have influenced the submitted work.

References