



Understanding and responding quickly to psychosis

*A guide for patients, families
and professionals*

Who is providing this guide?

Hafal is a leading Welsh charity supporting people with a serious mental illness and their carers. The charity is run by its Members, many of whom have experience of psychotic illness.

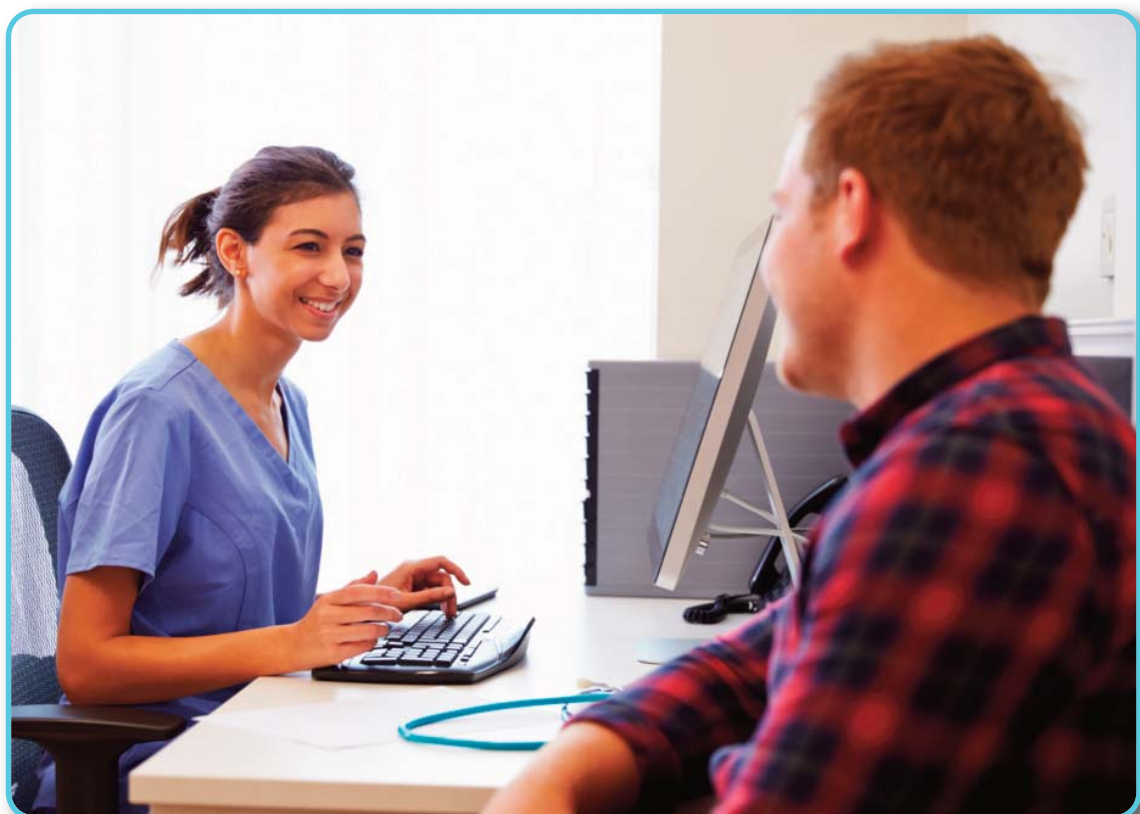
The advice in this guide reflects the experience of Hafal's Members; additionally we have been supported by experts in clinical and social care and by our HELP Panel - individual users and carers with experience of serious mental illness. We are very grateful to the Panel for their assistance in ensuring that the guide addresses the concerns of patients and families.

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Who is this guide for?

This guide is designed to assist:-

- patients who are experiencing psychosis for the first time (and it may also be helpful to those experiencing a repeat episode)
- their families and carers
- professionals supporting a patient with psychosis.



What is psychosis?

Psychosis means losing touch with reality through:-

- **Delusional beliefs** – including believing that other people want to do the patient harm (this delusion is called “paranoia”)
- **Hallucinations** – hearing voices or seeing (or otherwise sensing) things which are not really there
- **Other severely disturbed or confused thinking.**

Each patient’s experience of psychosis will vary: it is important that professionals supporting a patient with psychosis explain their specific symptoms clearly to them and to their carers.

What sort of illnesses involve psychosis?

People who have a diagnosis of the following illnesses typically experience psychosis:-

- **Schizophrenia**
- **Schizoaffective disorder**
- **Bipolar disorder**
- **Psychotic depression**
- Some forms of **personality disorder.**

This list is not exhaustive – other diagnoses may involve psychosis.

Note that psychosis is a *symptom* of serious mental illness so diagnosis will normally be made *after* a patient experiences psychosis – and the patient may still not have a specific diagnosis. However, people experiencing psychosis can be helped even if a conclusive diagnosis has not yet been made.

What causes psychotic illness?

Research has not so far identified definite causes for any type of psychotic illness.

There is increasing evidence of genetic links to psychotic illness though it has not been shown that specific genes lead to psychotic illness. But it is quite likely that a person’s genetic make-up may make them more susceptible to some psychotic illnesses.

Use of illegal drugs probably increases the chance of some people experiencing psychotic illness. It is also possible that a person’s life experiences may contribute to their chances of experiencing psychotic illness – but no clear “cause and effect” links have been identified.

Can doctors predict psychotic illness?

Extensive research is being undertaken into the causes and warning signs of psychotic illness but in the present state of our knowledge it is not possible to *predict* that a patient will experience psychotic illness through any kind of medical or psychological tests.

Sometimes a patient may develop unusual behaviours or experience seriously disturbed thoughts which a psychiatrist or other specialist can recognise as *likely (though not certainly) to lead to psychotic illness* – these are known as “prodromal” symptoms or as an “At Risk Mental State” (ARMS). There can be benefit in providing treatments for psychosis to people with prodromal symptoms/ARMS.

Can psychotic illness be prevented?

Because there is no way at present of predicting psychotic illness there are no direct means of preventing it - though preventive treatments may be developed in the future.

There is no evidence that supporting the wellbeing of the population as a whole – or providing treatment or support for people with less serious mental health problems – can prevent psychotic illnesses, although of course such evidence might be found in the future.

People can possibly reduce the risk of developing psychotic illness by avoiding illegal drugs.

In the specific circumstances where prodromal symptoms/ARMS are treated (see above) in some cases this treatment may help prevent full psychotic symptoms developing.

*More about **prevention** of mental illness:*

Everybody agrees that prevention is better than cure – and prevention has an important role in mental health. Taking care of your own or other people’s wellbeing (including: avoiding or dealing effectively with stress, anxiety, or sadness; having positive family relationships; engaging in satisfying employment or other meaningful activities; taking physical exercise; etc.) can prevent deterioration into mental ill-health. And this is not just a matter for individuals but also for families and for organisations which affect people’s wellbeing such as schools and employers: their good practice in supporting wellbeing can prevent mental ill-health.

This good practice by individuals, families and organisations helps everybody but, as indicated above, there is no evidence that it can prevent psychotic illness, even if it was possible to predict such illnesses. Prevention of psychotic illnesses may become a reality in the future – it depends on research into the causes of psychotic illness and finding a means of predicting such illnesses.

Can people be helped when they develop psychotic symptoms?

Because psychotic illness cannot be predicted or prevented (except possibly at the prodromal/ARMS stage) the key to getting the best outcome for the patient is to respond quickly when psychotic symptoms (or prodromal symptoms) first occur: this is sometimes called “Early Intervention” (EI) or, more specifically in this context, “Early Intervention in Psychosis” (EIP). There are two compelling reasons to respond quickly:-

1. There is clear evidence that if medical treatments aimed at treating psychosis directly are used promptly then the patient has much better prospects for *maximum possible recovery* in the long term. There are no “cures” for psychosis but many people get completely better and many others can recover to the point where they can manage very well; some people will need a lot of ongoing care and support but they too can benefit from having had early treatment.
2. Other forms of treatment including psychological therapies, plus timely “holistic” support and care across a wider range of matters, can help prevent lasting damage to the patient’s life in terms of career, education, social life, etc. – all things which also make a difference to the patient’s long-term recovery.

Quite rightly patients, families and professionals tend to look first to ensure the safety of the patient. But after that, in spite of the challenges and difficulties following the onset of a serious illness, it is worth trying to *get treatment in place, look ahead, and minimise disruption to the patient’s wider life.*

This can make a big difference to the patient’s long-term prospects.



More about *Early Intervention* and *Early Intervention in Psychosis*:

Early Intervention (EI) has a very broad definition and application in mental health. It can refer to a wide range of interventions made from a very early stage of mental ill-health. An example would be the provision of additional pastoral care or support for children showing signs of anxiety or other difficulty in school: this would not be purely “prevention” because it is targeted on a specific group already experiencing problems – so it could be defined as “Early Intervention”.

But, in our present state of knowledge, **Early Intervention in Psychosis (EIP)** can never usefully have this wide definition. Rather it can only realistically (and ethically) be applied to the narrowly-defined opportunity for intervention which starts **at the earliest** with identification of prodromal symptoms of psychosis or an “At Risk Mental State” (ARMS) but in many cases only starts with the identification of symptoms of psychosis itself. Note that the term “At Risk Mental State” refers to very specific, complex symptoms which can only be identified by an experienced clinician – the term should not be confused with more general signs of mental distress.

Because EIP can only be effective in this narrow window of opportunity there is an overwhelming argument for giving maximum priority to Early Intervention in Psychosis – a distinct priority which should not be confused with either prevention or early intervention in its wider sense.

Are there risks attached to treatments for psychosis?

Antipsychotic medicines are powerful drugs which often have significant side effects: in our present state of knowledge they can only therefore be used when there are clear prodromal symptoms/ARMS or symptoms of psychosis. Side effects vary between different antipsychotic medicines but they can include:-

- involuntary movements
- sexual problems
- tiredness
- weight gain
- diabetes
- depression
- cognitive impairment.

Some medicines also require frequent monitoring to check on side effects.

Nevertheless, where a patient is experiencing psychosis or prodromal symptoms/ARMS, the benefits of choosing an antipsychotic medicine will often outweigh the risk or actual experience of side effects.

The occurrence of side effects from medication makes it all the more important that patients and families are fully involved in choosing the right medication in partnership with doctors and then in managing any effects which they experience.

We recommend that patients and families request full information from their doctor or mental health team about the choice of antipsychotic medicines, asking about how they work but also what the side effects can be. Patients and families can also seek advice and information direct from an NHS mental health pharmacist – ask your doctor or mental health team for contact details. We also recommend that patients and families make use of the comprehensive information on treatments available from the National Centre for Mental Health:-

www.choiceandmedication.org/ncmh/

Psychological therapies, which are usually deployed after the more acute stage of psychosis has passed, should normally be safe but we strongly recommend that only properly qualified and supervised therapists are used. Patients and families should seek advice from their doctor or mental health team and they can also check professional associations including the British Association for Counselling and Psychotherapy:-

www.bacp.co.uk

So what can be provided at the point where somebody experiences psychosis?

Under the Mental Health Measure (Welsh law) patients in Wales with a serious mental illness are entitled to a Care and Treatment Plan which sets out treatments and other support which can be provided in order to help the patient maximise their recovery.

Hafal offers a detailed guide to developing a comprehensive Care and Treatment Plan which can be found here:

<http://www.hafal.org/wp-content/uploads/2016/04/CTP-Guide.pdf>

Additionally there are often some immediate actions worth taking when a patient develops a psychotic illness. Following the *areas covered in the Care and Treatment Plan*, these actions might include:-

• Accommodation

If the patient has their own accommodation then it is usually best to assume that they will want to continue to live there so long as it is safe for them to do so. In that case it is important to ensure that rent, mortgage, or other bills are covered. If they cannot keep their current accommodation then other arrangements may need to be put in place.

If there is a family carer involved they should think carefully about whether they should provide accommodation – this may be appropriate but equally there is often value in sustaining the patient's independence.



• Education and Training

If the patient is currently in education or undertaking a training course it may not immediately seem a priority to sustain this when they are dealing with an episode of psychosis. However, they may well be able to sustain or resume their education or training – and if they need to withdraw from education or training temporarily then it is often possible to negotiate with the provider to give them a break without losing their progress to date.

If the patient is not already in education or training then this may be a useful means of helping them get their life back on track.

• Finance and Money

Psychotic illness can itself lead to patients making poor decisions with money and indirectly their illness may lead to financial problems.

If they are unable to sustain employment then it is important to check out their benefit entitlements and ensure that they have sufficient resources to look after themselves.

• Medical and other forms of treatment including psychological interventions

Getting treatment quickly for a psychotic illness is not only important to secure the patient's immediate health but can also, as indicated above, greatly improve their chances of making the best possible recovery in the long term.

As well as medication to treat the psychosis directly doctors may prescribe other medication, for example for depression.

See also above *Are there risks attached to treatments for psychosis?*

Psychological therapy should also be considered as early as possible although it may be necessary for psychotic symptoms to lessen before psychological therapy can be used effectively.

• Parenting and caring responsibilities

If the patient has children or other caring responsibilities the immediate concern may be to ensure that they are safe and supported while the patient is experiencing an episode of psychotic illness.

However, it is important to sustain the relationship between the patient and those who they care for and, as soon as possible, to work out what support the patient may need to sustain their caring responsibilities.

• Personal care and physical well-being

Some patients will have difficulty looking after themselves in terms of things like bathing and changing clothes: support may be needed with these basics while they are experiencing psychotic illness. It is also important to consider their general physical health and try to sustain exercise habits and healthy eating.

The physical health of patients who experience a psychotic illness often deteriorates through poor diet and lack of exercise caused by their illness and sometimes as a side effect of medication. It helps to address this risk from the start by encouraging good habits of diet and exercise as the patient adjusts their life following an episode of psychosis.

• Social, cultural and spiritual

Friends can play an important part (short and long term) in helping the patient recover. Patients need to consider early on what they are going to say to friends about their illness and to seek their help and support as appropriate.

Patients from specific cultural and religious backgrounds may want to look for understanding and support from their own networks.

• Work and occupation

If the patient is in employment when they experience a psychotic illness then it is important to sustain that as far as practicable. Even if the patient becomes very ill it should be possible for them to report sick and keep their job open. This may not seem a priority at first but employment can be an important part of achieving recovery.

Many employers will be sympathetic but otherwise help should be sought to protect employment rights.

If the patient is not in employment or does lose their job following their illness then, as soon as the patient is ready, gaining employment can form part of their plan for recovery.



What about carers and families?

Carers and families provide a substantial proportion of the support needed by people who experience psychotic illness.

When a patient first develops a psychotic illness families and friends are typically put in the position of making rapid decisions about whether they can provide care and what level of support they can offer. Support can vary from quite light engagement such as making occasional calls or visits through to inviting a patient to move back into a family home.

It is important for carers to consider realistically what they can provide and to be clear about this to the patient and to health and social care staff.

If there are urgent or short-term needs then it is reasonable to put a time limit on a particular level of care which can be offered.

Carers can get detailed advice and guidance from Hafal's 10 Point Plan for Carers (www.hafal.org/wp-content/uploads/2015/03/10-Point-Plan.pdf) and they can request a Carers Assessment using Hafal's Carers Assessment Request Form (www.hafal.org/wp-content/uploads/2016/04/Assessment-request-A1.pdf).

What about the longer term?

This guide is concerned with the specific issue of early intervention but it is strongly recommended that patients and families start to look ahead to the longer term at the earliest opportunity.

A determination to get better and achieve the maximum possible recovery through holistic planning will assist both *practically* in addressing the real challenges and *psychologically* in cultivating a positive attitude.

Experiencing a psychotic illness *is* challenging – patients and families not only have to deal with the illness itself but they may also experience the stigma and discrimination concerning mental illness which has reduced in recent years but certainly persists.

But recovery is a realistic goal. Many people who experience psychotic illness make a complete recovery; many others can recover sufficiently to live their lives successfully with just a little help; others will need more help in the long term but they too can live rewarding lives with that extra support.

One of the best ways for patients and families to find their way on the journey to recovery is to compare notes with others who have experienced psychotic illness – follow the links below to get in touch with Hafal whose Members and clients are the real experts on mental illness.

Where can patients, carers, and families get help?

If you are reading this then you or somebody you care for is probably already under the care of a doctor or mental health services. If not, and you believe you or somebody you care for may be experiencing a psychotic illness, **do not hesitate to contact your GP or, if there is immediate risk to anybody, the emergency services.**

Patients who experience a psychotic illness will typically be seen first by their GP and are then referred for assessment by specialist mental health services; alternatively in an emergency their first contact may be with specialist services.

Ongoing support may be provided, depending on the patient's age and local circumstances, by Child and Adolescent Mental Health Services (CAMHS), Early Intervention Teams, or Community Mental Health Teams. If a patient needs continuing specialist support then a Care Coordinator will be appointed who is responsible for drawing up a Care and Treatment Plan with the patient and involving carers as appropriate.

It is important to ask your doctor and other staff to set out clearly who is responsible for providing support to a patient and to their carers. In addition it is recommended that patients and carers contact a reputable independent organisation to check whether the support being offered is timely and appropriate: they can also put you in touch with advocacy services.

Local contacts for Hafal can be found through this link: www.hafal.org/in-your-area/





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Hafal is Wales' leading charity for people with serious mental illness and their carers. Providing services in all the counties of Wales, Hafal is an organisation managed by the people it supports: individuals whose lives have been affected by serious mental illness. Find out more at hafal.org

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