

MAKING DECISIONS ABOUT YOUR TREATMENT FOR PSYCHOSIS

A DECISION AID

Aims of this booklet

The aim of this booklet is to help you focus on the choices you can make for managing your symptoms and difficulties. Using this booklet and working together with your doctor or care coordinator will hopefully ensure that you receive the treatment that is most suited to you. Although the focus of this booklet is mainly on medication, there are other important options that will form part of your treatment plan. These include psychological therapies and appropriate forms of support for you (and your family).

What is Psychosis?

Psychosis is not a condition in itself; it is a symptom of other conditions. Many cases are short-lived and may be single episodes. More severe cases may be diagnosed as schizophrenia or bipolar disorder. Drug or alcohol use can act as a trigger for psychosis as can some physical conditions.

We do not know enough about the causes of psychosis, but there are a number of things that have been shown to increase the likelihood of it developing. Psychosis can often run in families but the environment in which you grow up and live is also important and factors such as stress and drug use can act as triggers for an episode where people are already vulnerable.

The length of time that you may experience a psychotic state of mind depends on a number of factors. For example a sudden stress reaction or drug intoxication may only last a few hours or days whereas symptoms often persist for longer and sometimes need longer term treatment and support.

Symptoms

Psychotic episodes tend to be linked with four key symptoms. These are:

- Hallucinations
- Delusions
- Confused and disturbed thoughts
- Lack of insight and self-awareness

Hallucinations

A hallucination is when you think you perceive something that does not exist in reality. They can happen in all five of your senses.

Delusions

A delusion is having an unshakeable belief in something that is not based on logical reasoning or a person's cultural background.

Confused and disturbed thoughts

When people have an episode of psychosis the patterns of their thoughts frequently become confused or disrupted. Examples of ways in which it can change include the following:

- Speech might be fast and constant
- What they talk about may appear random and they might change what they are talking about in the middle of a sentence.
- Their thoughts may suddenly stop

Lack of insight and self-awareness

When people have an episode of psychosis they are often unaware that their behaviour is strange or that the delusions, or hallucinations they experience are not real.

Treatments

When someone is experiencing very distressing symptoms of psychosis and feels unable to cope, they may be prescribed medicine. The idea of taking medication may be scary to people who have not tried them before. The aim is to find the lowest dose that works. Remember, other types of treatment are also used, but this booklet is mainly about anti-psychotic medication.

Medicines may either be used in the short-term to treat symptoms of psychosis in order to prevent danger, or more often in the long-term to prevent relapse and help you stay well. The medicines used in treating psychosis are called anti-psychotic medications.

Antipsychotics work by blocking chemical effects on the brain. One important natural chemical is called dopamine. There are several types of antipsychotics; the two main categories are typicals and atypicals (also called first and second generation antipsychotics).

Atypical antipsychotics are normally recommended because they are less likely to cause troublesome side effects. However, they may not be appropriate, or effective in all patients. One medication called clozapine can be very effective when other antipsychotics have not worked sufficiently well. Clozapine can (rarely) cause serious side-effects and needs careful monitoring.

Other medications may also be recommended, including mood stabilizers (e.g. Lithium or Valproate), antidepressants such as fluoxetine (prozac) and benzodiazepines (e.g. diazepam or lorazepam) to calm distress or anxiety. Sometimes a medication can be prescribed to deal with specific side effects of antipsychotic medication, for example procyclidine or benzhexol for muscle stiffness and extra-pyramidal side-effects (see below for an explanation)

The length of time that you should take your antipsychotics for will depend on a number of factors but long term use is often recommended because it has been shown to prevent further episodes of psychosis.

Injections

Sometimes antipsychotic medication is given by injection, when it can be effective for 2-4 weeks at a time. A small test dose is given first and then further injections can be given by a nurse at home, at a clinic or at a GP surgery. Although some people don't like the idea of injections, this method can be very effective. You don't need to worry about taking tablets every day and you are less likely to stop medication suddenly, either deliberately or by accident and evidence shows that this is very important in helping you to stay well. The only atypical antipsychotic medication that is available in this form at the moment is risperidone. Risperidone long acting injection (RLAI) is given every two weeks but other "typical" injections are often used and some of these can be given every 4 weeks

Monitoring

Side –effects and effectiveness of medications need to be monitored in order to identify or prevent problems. Investigations which are part of routine health checkups are used, for example an ECG (see below), weight measurement, blood pressure and occasional blood tests are recommended.

When you decide to take a medication you will have a chance to regularly discuss how it is affecting you. You might like to discuss how the medication is working or any side effects. If there are any problems it might be appropriate to make changes to the dose of the medication, the time it is taken or the type of medication.

Side Effects

All antipsychotics are equally effective (except clozapine), so the side-effects are an important factor affecting choice of medication. The side-effects vary for different medications and some newer medications have less information available about them at the moment. The table below shows a comparison of the more common side-effects of the different atypical antipsychotic medications and how likely they are to occur.

Side-effect	Least likely to occur	Less likely to occur **	More likely to occur
Stiffness or involuntary movements	Quetiapine Aripiprazole*	Risperidone Olanzapine Amisulpride	Older (first generation) antipsychotics
Weight gain	Amisulpride Aripiprazole*	Quetiapine Risperidone	Olanzapine
Sedation	Risperidone Amisulpride Aripiprazole*	Quetiapine	Olanzapine
Sexual problems/ raised prolactin	Quetiapine Aripiprazole*	Olanzapine	Risperidone Amisulpride
Metabolic Problems*	Aripiprazole*	Amisulpride Quetiapine Risperidone	Olanzapine

* Not yet sufficient data for satisfactory comparison

** But may be a problem, particularly at higher doses

Stiffness or involuntary movements (extra-pyramidal side-effects): These include: akathisia (inner sense of restlessness and compulsion to move), tremor, muscle spasms, stiffness or tardive dyskinesia (abnormal movements- difficult to treat but fortunately rarer nowadays).

Weight gain: this occurs to some degree with all antipsychotics and of course underweight people may return to their normal weight after being unwell. The average weight gain over 12 months for those on quetiapine and risperidone is about 1-2kg. With olanzapine it may be considerably more. Advice and support with healthy eating may prevent significant weight gain.

Sedation: this can obviously interfere with energy levels and motivation. The impact can be reduced by taking medication later in the day, when it may help to improve sleep.

Sexual problems: These might include loss of sex-drive, reduced arousal and sometimes problems with erections or ejaculation in men.

Raised Prolactin: Prolactin is a hormone that is involved in the regulation of the breasts and can also effect periods in women. Raised levels do not usually cause symptoms but can result in breast enlargement, milk production (galactorrhoea) and fewer (or stopped) periods (amenorrhoea).

Metabolic Problems (Metabolic Syndrome): This may be partly linked with weight gain. Some medications can contribute to raised cholesterol and related substances in the blood stream. The body's ability to regulate blood sugar levels can also be affected but fortunately diabetes is only a rare complication. Blood tests are used to detect these problems early and they can be either be treated or else the medication can be changed.

Other Side-effects:

Low blood pressure (hypotension) can occur, and sometimes the pulse rate increases (e.g. with quetiapine) but this is not dangerous if monitored closely.

ECG (heart trace) changes can occur rarely. An ECG is recommended if there is a history of heart problems or if higher doses are needed.

Getting the most out of your doctor and care coordinator

Talking to professionals can be hard because consultations may have time restrictions and it can be difficult to communicate your concerns or ask questions. In order to get the most out of your meeting with health professionals it is important to be prepared. This can be done by thinking about your aims for the meeting and trying to stick to them.

What do I need to find out?

Take some time to answer the following questions as they will help you to identify what you know and what you want to find out, it can also highlight the areas you and your doctor or nurse might want to focus on.

Exercise 2

1. What do you currently know about psychosis?

2. What do you currently know about your medication choices?

3. What additional information do you want about psychosis?

4. What additional information do you want about medication for psychosis?

Power questions

'Power questions' are important and focused questions you can ask a health professional during your consultation. Preparing questions in advance will allow you to gain the most from your meeting. It can also help to make you more involved in decisions about your treatments.

Box 1 lists some examples of questions you might want to ask at your meeting, you might also like to come up with your own questions.

Box 1: Example Questions

1. *What medications are available to me?*
2. *How do the medicines work?*
3. *How effective are the medicines?*
4. *Which of the symptoms of my psychosis will this medicine help with?*
5. *What will happen to my condition if I decide not to take medication?*
6. *What side-effects might I experience if I take this medication?*
7. *What is the best way to prevent or deal with the side-effects I might get?*
8. *How long will I need to take the medication?*
9. *What happens if I stop taking the medication?*
10. *Will I need any extra health checks when I am taking the medicine?*
11. *How regularly will my medication be reviewed?*
12. *Are there any other treatment choices for me if I decide not to take the medications?*

Tips for getting the most from your appointment

Below are a number of tips that may help you to get the most out of your meetings.

Prior to your appointment

- Note the questions that you want answered
- Write down the details of symptoms, for example when they started, what helps and what doesn't
- Organise for a friend or family member to come with you if you feel this would help.

During your appointment

- Don't be afraid to ask for clarification if you don't understand
- Write down the important points you have discussed with the health professional

Before you leave your appointment

- Check you've covered the questions you brought with you
- Make sure you understand what you have discussed
- Know what should happen next
- Ask who you can contact if you have any questions or problems
- Ask whether there are any support groups and where you can obtain reliable information.

And finally..... the following websites may be helpful in answering any outstanding questions you may have:

<http://www.choiceandmedication.org.uk/>

<http://www.aspireleeds.com>