

What is Psychosis?

You may feel you don't fully understand what psychosis is. Alternatively, you may have been overwhelmed by information and can't work out what is important. This information sheet and the Module 1 of the REACT online toolkit aims to make things a bit clearer.

Psychosis is a mental health problem in which people appear to lose touch with reality. The most common ways this happens are:

- Believing things that are generally accepted to be untrue by other people. These are often called delusions
- Not being able to think straight and so sounding very muddled and confused, often called thought disorder
- Experiencing things that aren't really happening e.g. hearing or seeing things that other people can't, often called hallucinations

Psychosis is an umbrella term that covers lots of different conditions in which these experiences can occur. Your relative may have been given one of the following diagnoses.

Visit the REACT NHS website, (www.reactnhs.uk), for definitions and to find out more about of the following diagnostic labels:

- ◆ **Schizophrenia**
- ◆ **Schizo-affective disorder**
- ◆ **Drug induced psychosis**
- ◆ **Delusional disorder**
- ◆ **Psychotic episode**
- ◆ **Postpartum psychosis**
- ◆ **Bipolar disorder**

Positive & Negative Symptoms

You may hear people refer to 'positive symptoms' and 'negative symptoms'. This can be confusing, especially as it can be hard to see how any of these experiences can be positive. Over the page are definitions to help you understand what is meant by positive and negative symptoms

'Positive symptoms' describe experiences that are not usually present i.e. they are additional to what the person is usually like. The most common ones include:

- ◆ Hearing voices or noises that others can't hear,(auditory hallucinations)
- ◆ Seeing things that others can't see (visual hallucinations)
- ◆ Having strongly held unusual or bizarre beliefs that most other people would not share (delusions)
- ◆ Not thinking straight and therefore difficult to follow when talking (thought disorder)

'Negative symptoms' describe a lack of or loss of experiences that are usually there, i.e. they take something away from what the person is usually like. The most common ones include:

- ◆ Loss of motivation or energy
- ◆ Loss of pleasure in everyday activities
- ◆ Withdrawal from relationships and activities
- ◆ Negative symptoms are sometimes more difficult to understand and they can build up gradually. This makes them difficult to distinguish from:
 - ◆ Sedation effects from medication
 - ◆ Depression

To find out more about the cognitive problems that people can experience go to the REACT online toolkit

www.reactnhs.uk

What is Bipolar Disorder?

Some people are more familiar with the term '**manic depression**' – which is a different label for bipolar disorder but is often used to describe the same thing.

There are technically 2 types of Bipolar Disorder:

Bipolar I – both extremes of depression and mania.

Bipolar II – mainly depressed mood but with some episodes of a milder version of mania, called hypomania which may be less intense than full mania or only last for a short period of time.

Of course, everyone experiences ups and downs, but the extent of these is much more extreme and disruptive in Bipolar Disorder.

About **1 in 100 people** will have mood swings severe enough to be labelled bipolar disorder.

Some people also experience **mixed episodes**.

In a mixed episode you experience either:

- ◆ A full high mood/mania with some features of low mood
- ◆ A full low mood/depression with some features of high mood
- ◆ A full high and low mood at the same time

The frequency, length and severity of mood episodes are highly variable between individuals and over time. To find out more information go to the REACT online toolkit www.reactnhs.uk

Causes of Bipolar Disorder

It is still not clear what causes people to develop bipolar disorder. In fact, most people agree that it is unlikely to have one cause, and more likely to be the result of a combination of genetic vulnerability, life events, and particular styles of thinking.

Module 2: What is Bipolar Disorder?

1 2 What is Bipolar Disorder? 3 4 5 6 7 8 9 10 11 12

Causes of Bipolar Disorder

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What do depression or mania feel like?

Depression feels terrible. Here are some of the key features of depression.

- ◆ Low mood
- ◆ Problems concentrating
- ◆ Loss of motivation and energy
- ◆ Withdrawal
- ◆ Eating and sleep disturbances
- ◆ Loss of interest or pleasure

Mania. As mood goes up, many people go through a period of hypomania which can feel pleasurable at first. If mood escalates into full mania, this can feel very frightening and out of control.

- ◆ High or irritable mood
- ◆ Increased energy and Decreased need for sleep
- ◆ Distracted by racing thoughts and ideas
- ◆ Seeking pleasurable activity – sometimes risky
- ◆ Disinhibition – behaving ways considered outside the norm

No-one would ever choose to feel or continue to feel depressed or experience mania, if they could help it but It can be really hard to come out of .



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Module 3: Managing Positive Symptoms

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1 2 **3** Managing Positive Symptoms 4 5 6 7 8 9 10 11 12

Information Zone

Positive symptoms are 'positive' because they are an addition to a person's normal experience. Not because they are a good thing.

The main positive symptoms in psychosis are:

- Delusions (Beliefs obviously not true to other people)
- Hallucinations (Including hearing things, such as 'voices')
- Disorganised thinking (Literally trouble ordering thoughts, thoughts seem sped up, slowed down or muddled)
- Incoherence of speech (including new and mixed up words)

Delusions

Delusions are mistaken, implausible or in some cases, clearly bizarre or outlandish beliefs that develop in psychosis. Delusions range from exaggerated or 'over valued' beliefs that are common amongst the general population to those which can seem bizarre or implausible.

These are examples of exaggerated or overvalued beliefs that someone might experience:

- I have a special relationship with God.
- People are talking about me behind my back at work.

Examples of bizarre or implausible beliefs:

- God communicates to me through the words to rap videos on MTV.
- People at work have tampered with the air conditioning over my desk so that it sprays me with a gas that makes me dizzy.
- My husband is an alien who has taken human form and is planning to murder me so that another alien can take my identity.

It's important to recognise that delusions are usually **an attempt to understand an event or**



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Module 3: Managing Positive Symptoms

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1 2 **3** Managing Positive Symptoms 4 5 6 7 8 9 10 11 12

experience that is unclear or confusing. Therefore, they may have some basis in reality. To the person experiencing them, delusions feel entirely reasonable and no different to any other belief. Like anyone else, they might resent, or fight back against, anyone who challenges or ridicules their ideas.

Hallucinations

A hallucination is a perception that does not have a corresponding source in reality. The person might... See / Hear / Touch / Smell / Taste / Feel something that isn't there. The most common in psychosis is 'hearing voices'.

Hearing voices is quite a common experience, in the general population and for the most part, not a sign of psychosis. For some people, hearing voices is a positive experience, and they may even find the voices comforting or enjoyable. This is most likely when the voice is perceived to be coming from a friendly or supportive figure.

In psychosis, however, hallucinations tend to have qualities that make them hard to bear including:

- Frequent and difficult to control
- Refer to upsetting, personal or abusive themes
- Usually seem to come from outside the person and feel very real
- Make the person feel depressed, anxious, controlled

Why do hallucinations happen?

Hallucinations in psychosis seem to be caused by a breakdown in the ability to distinguish internally generated experiences from perceptions received from the outside world. So for example an internally generated thought, is heard as an external voice. To the person experiencing them, they are a real perception, not their imagination. Because voices seem completely real to the person it's normal for them to seek an explanation. This can often result in them developing delusional explanations, such as conspiracies, spirits or technological devices.

Visit the REACT NHS website, (www.reactnhs.uk), to find out more about different types delusions and how they develop.

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Module 4: Managing Negative Symptoms

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1 2 3 **4** Managing Negative Symptoms 5 6 7 8 9 10 11 12

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The term 'negative symptoms' refers to loss of normal behaviours. The most common include loss of emotional expression, loss of motivation, loss of pleasure in experiences or other people, and reduced levels of speech. Negative symptoms are common.

- No-one really knows what causes negative symptoms. One theory is that they emerge as a result of repeated experiences of failure and threat that result in the person losing motivation to explore their environment or seek support from others.
- Currently available treatments (medication and psychological therapies) are generally less effective in treating negative symptoms compared to positive symptoms.
- Negative symptoms of illness often cause the most stress and worry for other family members. They can carry on even after other positive symptoms have gone.
- People with negative symptoms may need extra practical help with looking after themselves. They need other people to understand that their negative symptoms are not due to laziness. Negative symptoms can also be difficult to distinguish from the effects of medication (because it makes people feel sleepy) and depression.
- Negative symptoms can make people more likely to try risky or illegal activities such as drug taking. They can't enjoy the things they used to, so they try and find something else to take the place of these.

Visit the REACT NHS website, (www.reactnhs.uk), to find out more about different types of negative symptoms and how others have learned to manage them.



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Module 4: Managing Negative Symptoms

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1 2 3 **4** Managing Negative Symptoms 5 6 7 8 9 10 11 12

Top Tips for managing negative symptoms

These are tips that other relatives have found helpful. Feel free to use the ones you like and ignore the ones you don't.

Tip 1 – Take Care of Yourself

This problem may last some time. To last the distance you need to pace yourself. Keep doing the things that keep you healthy, happy and out of debt. Keep your own life on track. Keep up with friends, work and family.

Tip 2 – Try Not to Show Your Frustration and Anger

This will only increase tension and makes everyone more jumpy. It may get things done today but makes it harder next time.

Tip 3 – Think About the Bigger Picture

For most people, recovery involves finding ways to get enjoyment and fulfilment out of life. The satisfaction of getting day-to-day jobs done isn't enough to motivate many people. But they might very well be able to find 'passions' to enjoy and get a sense of satisfaction from these.

Tip 4 – Try Not to Nag

Criticism, nagging or complaining about someone's behaviour can get them to behave better, but only in the short term. Psychosis can make people super-sensitive to criticism, too much of which could make symptoms worse in some circumstances. It won't make you feel any better either.

Tip 5 – Reward Every Effort by Making a 'Song and Dance' About it

Negative symptoms and thinking problems make it harder to do things without prompts. It's also harder to remember about things you've done well in the past.

Give clear and enthusiastic feedback for all successes and attempts. Make sure the person is surrounded by things which will remind them of the good things they have done.

Noticing and praising small steps towards recovery can really help.

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Module 5: Managing Mood Swings

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1 2 3 4 **5** Managing Mood Swings 6 7 8 9 10 11 12

Being a friend to someone who has extreme mood swings can be challenging. In this module we suggest some things that you as a relative can do that might help. These are based on our own experiences and those of relatives we have talked to. We can't promise they will all work every time, but we think they are worth a go. There are more ideas at www.react.nhs.uk and a forum to share suggestions with other relatives.

Support a Relapse Prevention or Staying Well Plan

Relapse Prevention and Staying Well Plans are useful for any mental health problem that fluctuates over time. Ideally a relapse prevention plan should be done with a health professional, who can also look out for early signs and be part of the plan to manage these. Ask your Care Coordinator or GP if you want to know more.

The important steps are:

- Identify and manage common triggers
- Spot early warning signs of changes in mental health
- Develop coping strategies to manage early warning signs and prevent them getting worse
- Understand what things keep us feeling well and make sure we do them

You can help with this plan in the following ways:

1. Anticipate the kind of events that trigger relapses and offer additional support at these times – eg work stress, relationship breakups etc.
2. Learn to spot early signs of a mood swing.
3. Be part of a Relapse Prevention Plan to manage early signs when they do occur. This might include how to communicate if you spot early signs, and what to do if a more severe mood episode develops.
4. Support regular social rhythms including sleep / wake times, eating and daily structure.



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Module 5: Managing Mood Swings

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1 2 3 4 **5** Managing Mood Swings 6 7 8 9 10 11 12

Being part of a Relapse Prevention or staying well plan can help your relative stay well, and can help you feel better because you know what to look out for and what to do if you are concerned.

You can only be part of a relapse prevention plan if your relative wants you to be which may change over time. If not, then it is likely that your attempts to get involved will lead to arguments and problems in your relationship. If this happens, you might try and agree that even if you are not involved in developing the plan, that you have contact details for the health professional and can contact them if you are concerned about a mood swing.

Try to Create a Low Stress Environment

There is now a lot of evidence that people with mental health problems are more likely to relapse if they live in households where there are a lot of arguments or they feel criticised. This kind of environment raises stress levels which can trigger mood swings.

Of course, it's easy to recommend this but often very hard to do. We all get cross and frustrated with each other at times. A few things that might help create a low stress environment include:

1. **Take time out.** If you feel yourself getting into an argument then just leave the situation and give yourself time to calm down.
2. **Acceptance is key.** When someone you love is unwell you naturally want them get better as quickly as possible. Accepting that you cannot make the mood swings disappear is difficult but important. Accepting that your relative is doing their best to manage their moods, even if their attempts don't seem to be working, is also important. This acceptance can free you up to provide support to help your relative recover in the time they need to do this.
3. **Hunt for the positives.** Being praised for doing something makes us feel great and more likely to do it again. Looking for small improvements and giving positive feedback on these can be very helpful, especially when someone is low in mood.
4. **Draw on the good times.** Bipolar disorder is a fluctuating condition. When things are bad it can be helpful to recall times when things were better, and to remember that the mood swings do come and go and that things will improve again.

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Module 6: Dealing with Difficult Situations

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1 2 3 4 5 **6** Dealing with Difficult Situations 7 8 9 10 11 12

We asked relatives and family what advice they would give for dealing with difficult and upsetting situations.

There are no 'dos' and 'don'ts' as every situation is different. However these are a 'try to' and 'try not to' list based on what other relatives and friends have found worked for them.

Try to	Try not to
<ul style="list-style-type: none">• Give sympathy and support.• Make sure that the person feels that you understand and love them and	<ul style="list-style-type: none">• Wrap them in cotton wool or try to protect them from everything.• Take on their problems.
<ul style="list-style-type: none">• Help with practical issues such as getting medication, getting to appointments, sorting out housing and bills.	<ul style="list-style-type: none">• Protect them from having to learn to do these things themselves. Make sure that the mental health services take a fair share of responsibility.• Give cash to people who run out of money repeatedly or spend it on drugs, alcohol or
<ul style="list-style-type: none">• Tell people how their behaviour affects you.	<ul style="list-style-type: none">• Deal with a problem when you are stressed. This risks you getting angry and making the
<ul style="list-style-type: none">• Help with the treatment that the person receives. Take part in groups or other meetings, such as care plan reviews when you are invited. If possible, insist you have a copy of the care plan if you do not already have one.	<ul style="list-style-type: none">• Insist or force the person to take medication or attend their appointments. This might only make relationships worse in the long run.



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Module 6: Dealing with Difficult Situations

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1 2 3 4 5 **6** Dealing with Difficult Situations 7 8 9 10 11 12

Information Zone

Up to 30% of people with mental health problems also have problems with drugs or alcohol

Generally speaking, taking street drugs or binge-drinking is associated with a greater risk of a person becoming involved in crime or violence

Having a psychotic illness makes a person slightly more likely to commit a crime or violent act. However, it makes it much more likely for the person to become a victim of crime or violence

Most families caring for someone with mental health problems face having to cope with some difficult behaviour. Here are some common ones relatives told us about:

Are any of these a problem for you? Are there any difficult behaviours you would add to this list?

Recommended Resources

Takes drugs

Is irritable

Makes a mess

Is 'clingy' or needs a lot of reassurance

Can't handle money

Is embarrassing or draws attention to

Drinks to excess

Threatens or is violent

Has bad habits

Hangs about with a bad crowd

Gets into trouble

Talks about death or suicide

The **Resource Directory** lists these resources and more but some websites which you may find useful include:

Oxleas NHS Trust have a factsheet for families about dealing with difficult behaviour.

This Scottish government website has a page where you can work through steps to manage stress:

<http://www.stepsforstress.org/recognising-stress.html>

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Module 6: Dealing with Difficult Situations

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1 2 3 4 5 **6** Dealing with Difficult Situations 7 8 9 10 11 12

Try to

Try not to

Say

“It really upset me when you swore at me”
or “We cannot tolerate you threatening your sister like that”

Get advice from experts or other families.

If you feel stressed or overwhelmed by a behaviour, walk away or take a break.

Arrange a family meeting to discuss it when everyone is feeling calmer.

Ask the person to make changes that might improve their behaviour.

Suggest that the positive change in their behaviour could be linked to something that they would like, such as a shopping trip or a hairdo.

Make sure that they don't get the reward or trip unless they at least make a genuine effort.

Help with the treatment that the person receives. Take part in groups or other meetings such as care plan reviews when you are invited and, if possible, insist that you have a copy of the care plan if you do not already have one.

Say

“You don't respect anyone anymore”,
“That's a nasty thing to say to your sister”

Expect the problem to go away on its own or hide it from others.

Deal with a problem when you are stressed. This risks you getting angry and making the situation worse.

Beg, force, blackmail or cajole.

Aim for things that haven't much got much chance of actually happening.

Make promises you can't keep.

Expect rapid change overnight.

Insist or force the person to take medication or attend their appointments. This might only make relationships worse in the long run.

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Module 7: Managing Stress - Doing Things Differently

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1 2 3 4 5 6 **7** Managing Stress (Doing Things Differently) 8 9 10 11 12

Ways to Manage Stress

You may want to try some new strategies to add to those you are already doing. Below are some common strategies that have worked for other relatives:

1. Focus on the Positives

What is going well? Sometimes, we focus only on the things that are going wrong, and forget about what is going well. Write a list of things that are going well for you.

2. Have Support Networks

Make a list of people you can talk to. They might be family, friends, healthcare staff, local support groups, local churches or any other groups who may offer what you need.

3. Work or Have Hobbies

Make sure you keep doing the things you enjoy. List the activities you do for yourself and what you get out of them.

4. Have a Break

You are only human and we all need a break sometimes. Write down the practical arrangements you would need to make to have a break/holiday. Find out about carer's breaks using the resource section of this toolkit.

5. Set Boundaries You Can Live With

You can't change other people's behaviour, but you can set some boundaries about what you are willing to tolerate. This isn't always easy and is a task that will require persistence – make sure your boundaries are realistic and that you are prepared to stick to them.

Visit the REACT NHS website, (www.reactnhs.uk), to find more Ways to Manage Stress and share what works for you on the relatives group forum



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Module 7: Managing Stress - Doing Things Differently

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1 2 3 4 5 6 **7** Managing Stress (Doing Things Differently) 8 9 10 11 12

Know Your 'Triggers' (Things That Make You Feel Stressed)

Common examples of stress triggers for relatives of people with psychosis or bipolar include the following:

- Having too many tasks to complete in a day
- Questions from friends who don't understand mental health problems
- Not being able to get hold of clinical or support staff when you need to
- Not knowing how to manage difficult behaviour
- Arguing about taking medication
- Thinking about all the things that all the family have lost as a result of the psychosis

Recognise Your Early Warning Signs (EWS)

For most people stress builds up gradually over time. Your ability to cope with situations feels like it is getting less and less. Being able to spot the very early warning signs that you are getting stressed means that you can do something to try and stop it getting worse.

As with the triggers, these are very individual and likely to be different for everyone.

Early Warning Signs (EWS) for stress might include:

- Being more irritable than usual
- Trouble getting off to sleep
- Not being able to concentrate
- Changes in your appetite
- Not going out to social events as much

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Module 8: Managing Stress (Thinking Differently)

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1 2 3 4 5 6 7 **8** Managing Stress (Thinking Differently) 9 10 11 12

Managing Stress— Thinking Differently

“People are not disturbed by things,
but by the view they take of them”

EPICETETUS
(GREEK BLOKE WITH A BEARD)



Here's what he meant...



Exactly the same event
can lead to very different
feelings, depending on the
view you take of it.

This is also true with
situations you are likely to
face supporting someone
with psychosis or bipolar
disorder.

There is no right or wrong
• it's just a different
perspective.

The important thing is that
the way you think can
have a big impact on the
way you feel.

There are some common
thinking traps that we can
all fall into, which make us
see the negative side of
things.

Event

You come home from work late afternoon and your
son/daughter is watching telly in their pyjamas.

Thought One

I can't believe (s)he is
not even dressed. I have
done a full day's work.

Feeling



Thought Two

Its ages since (s)he has
come downstairs to watch
telly with the rest of the
family. Maybe things are
getting slowly better.

Feeling



Module 8: Managing Stress (Thinking Differently)

REACT online Toolkit info sheet

1 2 3 4 5 6 7 **8** Managing Stress (Thinking Differently) 9 10 11 12

Common Thinking Traps

1. All or Nothing Thinking (Black and White Thinking)

A tendency to see things in extremes e.g. *'everything is absolutely awful and always will be'* vs *'everything is resolved and there will never be any more problems'*. The reality for most is somewhere in between i.e. pretty grey. Usually there are some things going well, and some things not. e.g. *'Some things have improved a bit, but there are still challenges ahead'*.

2. Jumping to Conclusions

This happens when we assume something (usually the worst) is true without real reason to do so e.g. *'the last medication / therapy didn't work so this new one isn't going to be of any use either'*. In fact it often takes many attempts to find the most appropriate treatment for each person.

3. Mind Reading

None of us can really read minds but we spend a lot of time pretending we can. We guess what other people are thinking all the time: whether they like us, whether they are interested in what we are saying etc. This is generally very useful as it helps us to communicate. It can also lead to errors when we assume people are thinking things that they are not e.g. *"He just lies in bed all day. He doesn't want to get better."* He might be in bed with a temperature, or really struggling with anxiety that makes it difficult to go out, even though he really wants to go outside.

4. Personalising

It's easy to blame yourself for everything that goes wrong. Many relatives blame themselves for causing psychosis, e.g. *'If I'd been a better parent then she wouldn't have got ill.'* There is no evidence that this is the case. There is also lots of evidence to support the role of many other factors such as genetics, trauma, drugs and stress. Many people with mental health problems have excellent parents and family carers.

We hope you found this useful—for more information go to www.reactnhs.uk

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Module 9: Understanding Mental Health Services

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1 2 3 4 5 6 7 8 **9** Understanding Mental Health Services 10 11 12

Carer's Assessment

Relatives providing support to someone with physical or mental health difficulties ('carers') also have a right to their own Carer's Assessment of needs and a plan of support.

This should follow the same 4 key steps described in development of the Care Plan, assess the same areas of wellbeing, and focus on achieving the same range of outcomes.

The Carer's Assessment can be done by the same mental health service as your relative/friend receives support from, or by a collaborating organisation. If you want a Carer's Assessment then ask the Care Coordinator to arrange this.

Even if your relative does not want support from mental health services, you are still entitled to an assessment of the impact of caring on you and your needs. Services have a legal duty to offer a Carer's Assessment at least once a year and it is the responsibility of the Care Coordinator to make sure this happens.

A Carer's Assessment can be extremely helpful in all kinds of ways so it's worth asking for. Remember, it is your needs that are being assessed. It's important you share any difficulties you are having and ask for support; no one is making judgements on how good you are as a carer.

You should be provided with a copy of your assessment. Check you are happy with it.

Making the Most of Clinical Meetings

Clinical services should involve relatives/close friends as key members of the care team. This includes inviting them to clinical meetings. You know the person best, are best placed to notice signs of relapse or change, and are likely to be supporting their staying well strategies. You may find that you have lots of questions that you want answers to but somehow you never seem to get the chance to ask them.

Visit the REACT NHS website, (www.reactnhs.uk), to find some strategies to help.



Your Early Intervention team can make sure you get access to the REACT online toolkit



www.reactnhs.uk

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Confidentiality

Talking with the health professionals about the person you care for can be difficult as staff may refuse to tell you some things because of 'confidentiality'. This can make caring for your relative difficult and can lead you to feel left out of their care.

Before staff can share some information with you, they need to have gained consent from your relative – i.e. their permission to share this information. This is important because your relative needs to feel safe in talking openly with mental health staff about their experiences.

There may be some information that your relative does not want you to know. This might be about their private experiences or beliefs.

The important thing is to find out what information staff **can** share with you, and what you **can** share with them. This is important because it ensures there is good communication between the people providing support. Information sharing is not 'all or nothing'. There is always some information that can be shared with you.

There are three main types of information:

General Information – this is what is available to the general public about mental health problems, treatment options and services that are available.

Staff can always share general information with you

Personal Information – specific information, such as your relative's mental health diagnosis, medication and their care plan.

Staff can share personal information on a need to know basis with careful consideration of the risks and benefits of this disclosure. For example, if you are named in the Care Plan as a provided of support, you need to know what this is.

Personal Sensitive – highly personal information, such as sexual orientation or personal views about their relationship with family members. Staff will only share this information when there is a risk involved in not doing so.

Module 10: Treatment Options

REACT online Toolkit info sheet

1 2 3 4 5 6 7 8 9 **10** Treatment Options 11 12

People with psychosis should be offered:

- A comprehensive multidisciplinary assessment in specialist mental health services
- A written collaborative care plan (service user should have a copy)
- Appropriate antipsychotic medication chosen by the service user and health professional together and based on a thorough understanding of the effects and side effects of the drug
- Structured psychological intervention (individual, group or family)

Relatives of people with psychosis or bipolar disorder should be offered:

- An assessment of *their* own needs and a care plan to address any identified needs (relative should have a copy)
- Advice about their right to a formal carer's assessment provided by social services as outlined in the Care Act 2015
- Written and verbal information about:
 - diagnosis and management of psychosis and schizophrenia / bipolar disorder
 - positive outcomes and recovery
 - types of support for carers
 - role of teams and services
 - getting help in a crisis

Visit the REACT NHS website, (www.reactnhs.uk), to find out more about different types of treatment which should be offered.



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Module 10: Treatment Options

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1 2 3 4 5 6 7 8 9 **10** Treatment Options 11 12

Psychoeducation

Psychoeducation is about providing service users and relatives or friends with information they need to understand and manage the difficulties they face. A key outcome is the development of a **Relapse Prevention / Staying Well Plan** developed through detailed analysis of previous episodes.

1. Identifying and managing common triggers

Triggers are situations which tend to occur prior to a relapse and are often linked to increases in stress levels e.g. taking on too much at work, or loss of an important relationship. Where possible, strategies are identified to help avoid / manage triggers in the future.

2. Spotting early warning signs are the very first changes that occur when a mood swing / psychotic episode is starting. If spotted these, and you can do something to manage them early, this can prevent a full relapse. *Common early signs you might see include:*

Mental health problems (general):

- Social withdrawal or isolation; not performing as well at school or work; low mood; anxiety; low motivation; poor sleep, decline in personal hygiene

Psychosis

- Suspiciousness; odd beliefs or magical thinking; unusual perceptual experiences (e.g., sounds seeming louder than usual or colours brighter); confused speech e.g. trouble following conversation or going off on a tangent

Depression:

- Low motivation; low energy; and feeling tired/listless

(Hypo)mania:

- Feeling energetic/very active; being more talkative; and feeling emotionally high

Visit the REACT NHS website, (www.reactnhs.uk), to find out more Key Outcomes.

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Module 11: Dealing With Crises

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1 2 3 4 5 6 7 8 9 10 **11** Dealing with Crises 12

Getting Help in a Crisis

These are the key points of contact in a crisis:

- **Crisis team.** Many services now offer a crisis helpline. If you do not already have the number, check the NHS Trust website. They are generally available 24 hours, 7 days a week. Staff are experienced in managing mental health problems and should be the first point of contact
- **Accident and Emergency department of your local hospital.** If your relative is willing to go with you to the A&E department it will be possible to see a Psychiatrist. Be aware you may have to wait a long time
- **Emergency Services (police or ambulance).** Where there is serious risk to people or property, you should strongly consider contacting the emergency services. Reporting to the police can be very hard when it involves a relative or close friend.

The Mental Health Crisis Concordant (2014) is a national agreement between services about how they will make sure people get appropriate help in a mental health crisis—below are four key areas that should make it easier for you as a relative or friend to get the right support in a crisis.

- **Access to support before crisis point** – making sure people with mental health problems can get help 24 hours a day and that when they ask for help, they are taken seriously.
- **Urgent and emergency access to crisis care** – making sure that a mental health crisis is treated with the same urgency as a physical health emergency.
- **Quality of treatment and care when in crisis** – making sure that people are treated with dignity and respect, in a therapeutic environment.
- **Recovery and staying well** – preventing future crises by making sure people are referred to appropriate services.



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Module 11: Dealing With Crises

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1 2 3 4 5 6 7 8 9 10 **11** Dealing with Crises 12

Crisis Plans

Unfortunately, crises tend to happen when help is hard to find, like during the night. It is a good idea to have a clear plan of what you would do at this time. The crib sheet below can help you develop a plan.

Important Things to Remember

Do

- Think about what you believe needs to happen and try to insist on this
- Be clear about what the potential risks are for your relative and others (family and general public)
- If you feel you cannot cope with the situation then state this very clearly
- Take the name and details of the person you are speaking to
- Write down the time and details of all conversations
- Insist on speaking to a more senior person or an on-call manager if you are not happy with the help that is offered

Don't

- Agree a course of action if you feel you remain at risk
- Overestimate your ability to cope without appropriate back up and support from services

Visit the REACT NHS website, (www.reactnhs.uk), to find out more about Dealing With Crises and a relatives group forum where you can share your experiences with other relatives

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Module 12: Recovery - Looking To The Future

REACT online Toolkit info sheet

1 2 3 4 5 6 7 8 9 10 11 12 The Future

Common Concerns For Relatives

Stigma and identity

Unfortunately there is still a stigma attached to mental health problems in our society. This can make it difficult for people with these kinds of problems and their relatives to talk openly about their experiences. 'What should I share with whom?' is a common concern.

Some people are happy to identify themselves as having (or have had) a mental health problem and can talk openly about these experiences. Others share with some carefully chosen close friends or employers, and others choose not to share. This is a very individual choice and depends a lot on the broader situation. It's a complex issue and one that you may also struggle with as a relative/close friend.

Recognising the complexity and opening up the opportunity to discuss it may be helpful.

Moving on from mental health services.

Recovery often involves reduced support from clinical services. This can be difficult as you may have come to depend on this support and feel anxious about it going. Ideally, reduced input from services occurs gradually and at the same time that links with other support networks are being built up. These might include other mental health services such as voluntary sector groups, or networks formed through hobbies, and friendship groups. The timing and pace of this transition is important.

It can be helpful to discuss with the clinical team in advance how and when this process will happen. If you are concerned about the timing of this, then it's important to raise your concerns with the team. It's also important to find out how you can get back in touch with the services in the future, if the need arises. So for example, can you contact them directly or is a new referral required?



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Module 12: Recovery - Looking To The Future

REACT online Toolkit info sheet

1 2 3 4 5 6 7 8 9 10 11 12 The Future

Your Own Recovery

Becoming a relative or close friend of someone with psychosis or bipolar disorder can be a very difficult and sometimes traumatic experience. It is not something you plan to do, and you won't always have the information and skills available to deal with it straight away.

The impact on your own work life, hobbies, and other relationships can be significant, and the emotional impact devastating. This is particularly true for those with a very close caring role.

It may be helpful to think about your own Recovery journey and what you need in order to rebuild a satisfying, hopeful and contributing life for yourself. Some of the things that other relatives have highlighted in being important in doing this are:

1. Making time to do other things and spend time with other people. This can get neglected when caring demands are high. If this does not feel possible, think about what might need to change to make it possible.
2. Getting support from other people. This might be extra support for your relative/friend so that this role is not being done by you alone, but also for yourself. Support may come from other friends, family, or services.
3. Despite the very many challenges that supporting someone with a mental health problem can present, some relatives report that positive things have come out of the situation and recognising this has been helpful. Examples have included:
 - Learning about something you didn't previously understand
 - Learning about yourself (or your relative) and your capacity to cope with difficult situations
 - Developing closer relationships with other people (possibly your relative/friend)
 - Developing greater empathy and understanding of people in distress
 - Being more empathic towards people in need

Visit the REACT NHS website group forum to find out what has worked for other relatives

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