PSYCHOSIS: AN INFORMATION BOOKLET

This booklet is for people who may be having contact with a mental health professional, team, or service, as well as the people around them: family, partners, close friends, people they live with.

The booklet describes experiences that may be considered unusual or out of the ordinary. Sometimes, some of these experiences are not as unusual as they may seem, and are also experienced by many people not in contact with mental health services. They may not cause any problems, or may go away on their own. For children and young people, they may be part of normal development.

Sometimes, the experiences do cause problems, for the person having them or the people around them, or both. The difficulties can be severe enough to bring the person into contact with mental health services. Sometimes the person may need emergency help or some time in psychiatric hospital.

The experiences can happen on their own, or with other mental health problems, like anxiety (feeling unusually scared or worried a lot of the time) or depression (feeling unusually low or down a lot of the time). They are common for people who have neurodevelopmental conditions such as people who are on the autistic spectrum, and for people who have longstanding problems with their own emotions and relationships with other people. They can also be linked with upsetting or stressful life events, with using alcohol or drugs, or with physical health changes.

Sometimes, the experiences might be the symptoms of a recognised mental health problem called *psychosis*.

This booklet contains information about psychosis and unusual or ‘psychosis-like’ experiences, including possible causes, recommended treatments, and other things that might help. You may find some of the information fits with some of the experiences you have had or experiences you have seen in others. You may find none of it fits at all.

The booklet is just one way of thinking about the experiences. People often have their own strong views about what is happening, what it means, and how to manage.

Different views and ways of trying to manage can cause disagreements between the person, the people close to them, and mental health services. This is very common. You have not been given this booklet to persuade you to think a certain way. The idea of the booklet is to present the information, so you can discuss how it may or may not apply in your situation, and how you, the people close to you, and mental health services, can all manage most helpfully, even when there may be different views.

WHAT DOES PSYCHOSIS MEAN?

- Psychosis is a change in how a person experiences themselves and/or the world around them. It can change how people sense things (what they see, hear, taste, smell or feel) and their thought processes. It can change how someone feels, and how they behave. Psychosis may be experienced very differently for different people, at different times, and in different situations.

- Psychosis is a general term, and can happen on its own, or be linked with other conditions or events. Psychosis is not a diagnosis (i.e. a medical label for conditions with similar causes and treatments). This means that just having psychosis or psychosis-like experiences does not mean a person has a particular mental health condition.

- However, psychosis is a common part of some mental health conditions or diagnoses, such as *schizophrenia, bipolar disorder (sometimes called manic depression), schizoaffective disorder* or *drug induced psychosis*. Different names are used depending on changes in the person's emotions and whether the psychosis only happens after a mood change or another trigger, how long the problems last, and the kind of experiences the person has.

HOW COMMON IS PSYCHOSIS?

- ***Anyone,*** whatever their gender, race, religion or social class can experience symptoms of psychosis. On average, around 3 out of every 100 people during their lifetime will experience an episode of psychosis, making psychosis half as common as diabetes.

- Some experiences are much more common than this. For example, in surveys, as many as 40% of people have reported hearing voices, and most of them do not have contact with mental health services. Experiences that bring people into contact with mental health services tend to be more frequent and distressing.

- Psychosis commonly starts in younger people during their teens or early twenties. This may be linked to changes in the brain as it matures. It is also a time of life changes for many people that may increase stress. However, psychosis can also start later in life.

- Higher rates have also been reported in people who have been through a traumatic life event or other very stressful life experiences.

- People changing countries, and the children of people who have changed countries experience higher rates of psychosis: this may be related to the

stress of leaving a country, settling in a different country, and adjusting to a different culture.

WHAT EXPERIENCES ARE COMMON IN PSYCHOSIS?

The common symptoms or experiences of psychosis are often grouped together into three or four categories. People might have symptoms from every category, or just one category, and this can change over time.

Positive symptoms means having unusual sensory experiences or unusual beliefs.

Hallucinations means hearing, seeing, smelling, feeling, or tasting things that others do not.

- Although hearing things (auditory hallucinations) is most common, hallucinations can happen in any of the senses.

- Auditory hallucinations may be noises or voices, and can be just one noise or voice, or several. Sometimes people can hear many voices together, like a chorus, or a crowd.

- Voices may be constant or may come and go. They can be louder and quieter at different times, and may sometimes be clear and make sense and other times be hard to understand.

- Voices can talk to the person (saying ‘you’), or about them (saying ‘he’, or ‘she’, or referring to them by name).

- The voices may seem to be coming from inside or near to the person’s own head, or further away – in the room or outside.

- Voices can sometimes be hard to tell from the person’s own thoughts, that can sometimes seem especially ‘loud’, but usually the person experiences the voices as separate from their own thoughts, coming from someone or something else.

- The person may recognise the voice: it may sound like someone they know or used to know, or someone they have heard before. Sometimes, the person is sure who the voice belongs to and why it is happening: other times it can be less clear.

- Voices often say upsetting, rude, or distracting things, that affect how the person hearing them feels. They are often very hard not to believe or to ignore.

- Voices can sometimes say funny or positive things, that can make the person hearing them laugh or smile unexpectedly, or in situations when they wouldn't usually laugh or smile.

- People may feel like they have to listen to the voices, and often respond by talking back or shouting, even if other people are there.

- Voices may tell the person what to do and people may feel like they have to do what the voice says or something bad will happen. Voices may tell the person to do things that seem odd, or things that are dangerous and very extreme. Sometimes people try to do a part of what the voice tells them to do. For example, they might hurt themselves in some lesser way, when the voice has told them to kill themselves.

- People may also see things like figures or images, smell unpleasant things like body odour or faeces, or feel things inside them or on their skin: feeling something crawling, like an insect, is especially common.

Other unusual perceptions

- People can also experience stronger or more vivid perceptions, like colours seeming brighter or more intense, or noises being louder and more surprising.

- Events can take on a special, personally relevant meaning, when they may seem to others to have no connection with the person.

- Events may connect with each other or be unusually attention-grabbing in a way that is not obvious to other people.

- People may experience time as faster or slower than usual.

- The outside world may be experienced as changed in some way - unreal, or not quite right. The same can happen for people. In particular, familiar people may look or feel not right, making the person worried they are not who they say they are. The person can sometimes find the same thing happening to themselves, experiencing themselves as changed or different in an important or significant way.

- Things that are usually private, like thoughts or memories, can be experienced as available to other people. People may also have experiences

that they believe are other people's private mental events, that they have been able to access, like thoughts or dreams.

- People often report a sense of being watched or monitored, or of a presence near them, so that nothing ever feels private. This can be especially distressing during personal activities, like bathing or using the toilet.

Changes in thinking, feeling, and acting

- Thoughts can also be speeded up or slowed down, or the flow of thought can change.

- People can experience all their thinking suddenly stopping, so they have a complete absence of thought.

- Sometimes the experience is of thoughts being pulled from the person's mind, or happening outside the person's mind (which can also lead to worries about privacy).

- Changes in thinking are often reflected in how the person speaks, and can make interacting more difficult.

- Thoughts and feelings can be experienced as not the person's own, coming from someone or somewhere else.

- Movements can also change in their flow, and people may find themselves stiff, jerky, or restless in their movements, getting stuck in certain positions, or unable to move. This can be very scary.

- Movements can also be experienced as not the person's own, as though someone or something else has made them move.

Unusual beliefs that the person is often very certain about, but that seem untrue to other people, are very common in psychosis.

- Unusual beliefs are often ways of making sense of unusual experiences, and may seem to the person like the most convincing explanation for what they have experienced.

- People's unusual beliefs may also be related to events in the outside world, or in their own lives, or to religious, cultural or spiritual experiences or beliefs.

- People commonly worry about other people's intentions, and that they cannot be trusted or mean to hurt them in some way. This can happen in

relationships that used to be very close or trusting, and the change can be very upsetting.

- People may also believe that they are different from others, sometimes in a special way, like they are particularly important. Sometimes people believe they are particularly bad or have done something they feel very guilty about.

- Unusual beliefs may also be called delusions. It is not usually helpful to argue with somebody's belief, even if you can see it is upsetting them, and you are certain it is untrue. Arguing can make the person feel upset, and more sure about the belief. In some ways, this is like any other strong belief or feelings, for example arguing with a football supporter about who they support is unlikely to make them swap teams! It is usually more helpful to find a way to agree to differ. There are some ideas later in this booklet that you may find helpful.

Disorganised symptoms are changes in the person's ability to plan, organise and manage things.

- People often report finding it hard to keep their train of thought or the thread of a conversation, or to concentrate and keep their attention focused.

- The person may feel like their thoughts are jumbled, and it can be hard to communicate what they mean to others.

- The person's way of talking might change, so that they give a lot of detail that may seem irrelevant to the person they are talking to, or change from one idea to another.

- Sometimes the person may use words they have created themselves, that are hard for others to understand.

- It can be much harder for people to plan the steps of a task: even everyday things can seem quite overwhelming and complicated.

- It may be particularly hard to maintain a routine like regular getting up, going to bed, and meal times, and the person may need lots of reminders about appointments and other arrangements.

- Emotional reactions may seem to come out of the blue and be very changeable: the person may find that their feelings do not fit the situation, and change quickly and apparently without reason.

- People can also find themselves doing things unpredictably without an obvious reason.

Negative symptoms means usual experiences being absent or dampened down in psychosis.

- People often report feeling less energetic or less motivated. This can be very extreme, to the point that people can no longer experience a feeling of motivation or of having any energy in their body. Research has shown physiological changes related to this in people who have psychosis.

- People may seem to look forward to things less and be less interested. This can include activities, but also interpersonal things, like being with and talking to other people. It is believed that the usual chemical / brain systems that make us feel good when we look forward to nice things, is disrupted in psychosis.

- Sleep patterns are often disrupted: people often sleep much more, and seem tired a lot of the time. People may find themselves awake and asleep at completely different times from usual, or from the rest of the family and this can be very difficult. For some people, sleep may be a way of coping with difficulties, or some medications can make people feel more sleepy.

- It can take a lot of prompting and help for the person to be able to get started with things, and once started, they may find they get tired or lose interest more quickly, take a very long time to do things, or need more help.

- It may be hard for people to find things to occupy themselves, and while some people may be content to do not very much, others may make more demands on the people around them, to spend time with them. This can also happen if the person does not feel safe on their own.

- The lack of interest can extend to the person looking after themselves. It is common for people to seem to care less about their personal hygiene and appearance, and people may fall into patterns of wearing the same clothes without changing, wearing unusual clothes, or clothes unsuitable for the weather (e.g. a heavy coat in summer).

- People may become more sensitive to any kind of change around them, such as their belongings being moved or other changes in the home.

- People may seem less emotional generally. Relationships can seem much less warm, and you may feel less connected, or like the person cares about you less. However, it is often the case that, although people are struggling to express their emotions in the same way, they still feel them. In particular, people with psychosis are very sensitive to negative emotion and tend to easily feel criticised, and this can worsen their condition.

- Carers and families often struggle to understand negative symptoms as it can seem like the person doesn't want to 'get better' as they don't seem to want to do the things that would normally make them feel better. Families often assume that negative symptoms, which are often experienced after positive symptoms have subsided or become less intense, are because the person is a bit depressed about what they have been through. It may be that the person is also feeling very low because of what has happened to them, but negative symptoms are different from depression.

- People can and do recover from negative symptoms but the recovery sometimes takes longer than recovery from positive symptoms

Emotional changes are the fourth group of symptoms.

- Psychosis is often accompanied by emotional problems such as low mood or anxiety. High mood (or 'elation') and anger or irritability are also common.

- The person's emotional responses can feel more out of their control and harder to cope with – they can seem much more sensitive and unpredictable in their emotional reactions, or, sometimes, flatter and less emotionally responsive.

- Although this can be very difficult, it is helpful if you can avoid taking it personally: the person's usual feelings may have been changed by their experience of psychosis and they may not be able to be their usual self.

- You may find that somebody becomes aggressive once they have psychosis, although having psychosis does not necessarily mean a person will behave in a threatening way.

- It is important if this happens to seek advice and help so that you can all feel safe if someone is behaving aggressively. It is also important to remember that people with psychosis are more usually victims of aggression than perpetrators of it.

- People may also seem more withdrawn, and agitated, anxious, or uncomfortable when they are with others. They may prefer to spend long periods of time on their own, when they may not seem to do very much, and spend less time with the family, or be less involved in family activities. It can help to be as relaxed as you can about this, encouraging the person to join for as long as they are comfortable, and not making a big deal if they want to leave, even on important occasions.

Behaviour changes are common in psychosis.

- As well as the changes noted in the sections above, people often do things to try to manage their experiences, that may seem odd to others.

- They may play loud music, or have the TV louder, at unusual times to manage voices.

- They may talk or shout back in response to voices or other experiences, or do other things as a reaction to voices.

- Because experiences often involve threat, people may take unusual precautions, like staying indoors or even hiding, keeping windows and curtains closed, wearing certain things, taking particular routes, or only going out to particular places or at particular times.

- People sometimes use alcohol or drugs – to help manage their experiences, or for other reasons (like relieving boredom, or to stay connected with a social group), and this can also lead to behaviour changes.

WHAT ARE THE CAUSES OF PSYCHOSIS?

- Current thinking is that psychosis has biological, social, and psychological causal factors (a biopsychosocial model).

- There does not seem to be any one single cause. Rather, several different factors all seem to operate together to increase the risk of psychosis, like having an underlying vulnerability, then experiencing a stressful life event (a vulnerability-stress model).

- Which factors are involved and how much will vary from person to person.

- Factors linked with the development of psychosis also seem to be associated with unusual experiences, and with people having further episodes of psychosis after they recover.

Biological factors

- Genetics and a family history of psychosis seem to influence vulnerability to psychosis. People with a close relative with psychosis, like a parent or sibling, are more likely to develop psychosis themselves. Having a more distant relative with psychosis, like a cousin or aunt/uncle, does not seem to increase the risk.

- However, genetics are not the sole cause of psychosis. Even with a close relative with psychosis, nine out of ten people will not go on to develop

psychosis themselves. People with psychosis are usually the first in their family with the condition.

- The chemistry and structure of the brain in people with psychosis differs from people without psychosis. Some research suggests that brain changes in adolescence occur differently in people with psychosis. However, the cause and meaning of the changes is unclear. For example, we know that people with psychosis have often experienced adverse early life events, and these can affect the developing brain. It may be that the changes make the person more vulnerable to future stressors.

- A lot of the experiences of psychosis are like experiences related to changes in brain chemicals and particularly dopamine. Dopamine is involved in signalling to the brain what is important to pay attention to or plan for and work towards. It is also involved in starting off and keeping the pace and flow of actions (both physical actions, like moving and mental actions, like thinking). Many medications for psychosis work partly by affecting dopamine activity.

Psychological factors

- Throughout our lives, we learn from experience, and develop beliefs about ourselves, the world and other people that influence our day-to-day functioning.

- We also vary in our biological functioning or temperament (like some people are more emotionally sensitive than others), and our thinking style.

- These factors can influence how likely we are to develop mental health conditions, and how we react to and manage difficulties.

- Some experiences of psychosis, for example, seem to be linked with particular beliefs about the self and other people, and particular thinking styles (e.g. relying more than usual on fast (or emergency) thinking, rather than weighing all the options before deciding something).

Social factors

- Stress and stressful life events seems to be one of the main factors contributing to psychosis.

- People with psychosis are more likely to have experienced more adversity in their life, including in childhood, especially being hurt in some way by another person. They are also more likely to have experienced a life-threatening

trauma. The more adversity a person has experienced, the greater the risk of developing psychosis.

- However, there are also many people who develop psychosis without experiencing any unusual stressors.

- Psychosis also seems to start, and recur, at times of life change, which can create stress – for example, moving out of the family home, starting and ending relationships, starting a course of study or changing job.

- Using drugs, particularly cannabis, and alcohol, can increase the risk of psychosis. However, it seems to be for people who have a genetic vulnerability that this occurs: very many people use drugs and alcohol without developing psychosis.

- It is important, therefore, not to think of the substance use itself as having caused psychosis – it is the combination of vulnerability (which the person is unlikely to know in advance) and substance use. It can be helpful for families of people who develop psychosis after using drugs to think of this being down to bad luck and genes, rather than blaming the person's behaviour.

- As well as changing countries or cultures, living in the inner city seems to be linked with psychosis. It is thought that this might be to do with the stressors of city life: there are more people, traffic, and noise to handle, and often less good quality of life (e.g. more poverty, poorer housing, crime).

Families and psychosis

- For anyone experiencing, or living with/caring for someone experiencing, anything we discuss in this booklet, the most important message is that you are not to blame. No one is to blame for psychosis, any more than they would be to blame for a serious physical illness. The good news, is that while you are not blame, there are some things we know that individuals and families can do to help with recovery...

- Family contact can be especially important for people with psychosis, as it can be hard to keep up with other social contacts. People with psychosis who are in contact with family often have better outcomes than people with no family involvement: this could be for a range of reasons like providing support, and spotting early if things are getting more difficult for the person.

- However, if relationships in a family are very difficult, it can also help to get some space from each other. Spending some time apart and having independent lives is always important, but living separately can also be more helpful than trying to keep going with an unmanageable situation.

- Many families feel guilty about things they think may have caused a person's psychosis. Traumatic events in childhood may increase a person's risk of developing psychosis. However, there is no evidence that families themselves can cause psychosis.

- Stressful interactions can make symptoms worse for a person with psychosis. It is really useful to be mindful of how you talk and behave with each other day-to-day as we know this can be actively helpful in the person's recovery and avoiding future episodes. Because families are often trying to manage other things in their lives as well as psychosis, this can be very difficult. Families and family interaction do not cause psychosis, but calm and supportive family interactions can significantly improve recovery for people with psychosis. There is no such thing as a perfect family!

RECOVERING FROM PSYCHOSIS

- Most people experience some degree of recovery after having had psychotic experiences.

- For a few people, the symptoms improve on their own or with treatment, and they do not have another episode.

- Most people experience further episodes of psychosis, often at times of crisis, stress, or change, but find things are better in between episodes.

- How much better things are between episodes varies from person to person. Some people find they are able to get on with normal life, with very few adjustments. Other people may find they need to make more significant changes, like choosing less stressful work or study, or working shorter hours.

- Some people find they are not able to work, but can find worthwhile creative, vocational or leisure activities.

- People's ability to form or maintain relationships after psychosis can also vary: some people find they have very few problems, while for others, meeting people and maintaining relationships feels like an overwhelming stress and not achievable.

- Some people may be more sociable or trusting, making people around them worry that others may take advantage of them. People may need help to understand and make equal and mutually supportive relationships.

- For a small number of people, psychosis seems not to respond very much to treatment, and it can be hard to find meaningful or enjoyable things to do.

- Recovery is often slower than people or their families expect and this can be frustrating, disappointing, and worrying. Recovery can also be very unpredictable: things may seem not to be changing, then get a bit better, or improve and then get worse again. This can also be very hard for the person with psychosis and the people around them.

- The signs of a slower recovery can be harder to spot than when somebody has more unusual psychotic symptoms. Negative and disorganised symptoms can be less obvious to other people, but very disabling. People may find it still takes them a long time to do things, or that they are much quieter, more tired, or find things more stressful for a long time after other symptoms have improved, and they may need some support for longer than expected. The person may not be as involved in family life as before and spend more time alone.

- For family members, it can help to think of recovery as a marathon rather than a sprint, and try to build support into their lives alongside other things that are important to them, so that they can keep going, rather than dropping everything to care for the person, then feeling pressure to stop and get back to normality. This is difficult, and the balance is different for different people.

- Though it can be difficult, it is important not to take the changes personally. They are usually the person trying their best to cope with difficult and distressing experiences, rather than anything done to deliberately upset you.

- The most helpful way to approach recovery seems to be to keep up hope that things can improve, even if they have not for a very long time, and be supportive and encouraging, but, at the same time, to be patient about slow change, taking things in very small steps, and taking steps back as well as steps forward. This is a very tall order for anybody, and almost impossible to manage to do all the time, so it is important for family members to try to look after themselves and be kind with themselves as much as possible.

TREATMENTS FOR PSYCHOSIS

Medication is the most common treatment to be offered for psychosis, and mental health services will usually recommend that you take medication.

- The medication you are offered will depend on the pattern of your symptoms, and, if you have taken medication before, what has and has not suited you in the past. Your physical health and characteristics will also considered.

- Some medications need you to take tests, for others there may be special guidance about how to take them. Medication can be offered as tablets, liquid, or an injection and the doses vary depending on the type of medication: what sounds like a lot can actually be a very small dose and vice versa.

- It is important to take the medications as advised: if you have any concerns about them, you should talk to your doctor and make changes only with medical advice.

- The medication works by balancing out changes in brain chemicals. This has different effects for different people. It can make experiences like voices less intense and bothersome, or can help you feel less preoccupied and worried. Some people feel calmer, or find it easier to think and concentrate. Some medications also help with other psychotic symptoms. It can take time for the medication to have an effect, and to find the right dose for each individual.

- You should always speak to your doctor or other healthcare professional if you feel the medication is not helping, or if you feel unwell taking it. Common unwanted effects of medication include tiredness, lack of energy, changes in appetite and weight, changes in sexual functioning. Sometimes these get less over time, or by changing the dose of medication, or when and how you take it. However, it may be that a different medication will suit you better.

- Unfortunately, it is not possible to tell in advance what medications may suit a person, and finding the best one for you may mean trying out a few. People sometimes find that this approach feels like being a ‘guinea-pig’, but it is often the best way to find the right choice of medication for you.

- The best choice of medication for you will depend on your individual preferences as well as how the medication affects you. For example, some people hate feeling drowsy, but may not mind feeling a little restless, some people will feel the opposite.

- The choice may also change over time – sometimes because you may change physically, or your circumstances change, sometimes because there is new information about the medication, or new medications become available, but sometimes for no obvious reason. It can sometimes feel like an opportunity to make a change and try something new that may be more helpful, but can also sometimes feel like a nuisance if you have felt settled on a particular medication.

- Sometimes people find that they do not notice any change from taking the medication, or even feel worse, while people around them, like family members, or the team, say that they seem better when they take it, or are

afraid that even if things are not much better, they will get even worse if the person stops medication. People may also feel afraid in this way themselves. Different views about medication often cause tension. It can be helpful to talk carefully through each point of view to try to find a way forward together.

- There may also be differences of view about the best way to take the medication – some prefer, and feel they have more control, taking tablets; others prefer taking an injection once each month and not having to think of medication the rest of the time. Again, talking through the reasons for the preferences can help.

- As well as helping with current experiences, medication can also have a protective effect, making people less likely to react strongly to future stressors by balancing out changes in brain chemicals. Stopping medication can increase the chances of another episode. For some people things can change very quickly if they stop or adjust their medication. For others it may take a while, and some people do not notice much change at all. Again, other people may notice changes when the person themselves does not feel any different, or may experience different changes.

- It is usually recommended that people stay on mediation for some time, often a period like two years. For many people the recommendation is to continue taking the medication longer term. The longer term plan is usually to find the minimum possible dose of the most suitable medication for the person – but this can take some time to work out. Taking it for so long can be upsetting for some people, especially if things seem to have got better, when it might feel the medication is less needed, or if it seems not to make much difference. It can help to think of psychosis medication as similar to medications taken for long term physical health conditions: the medication is often working in the background, rather than on the most obvious symptoms.

Talking treatments

- Everybody with psychosis should be offered the chance to talk through their experiences, how they affect them day to day, and any psychological strategies that might help. This should be offered individually, but there might also be groups that the person is invited to join.

- People who have family members involved in their care or living with them should be offered chance to talk together as a family about how the difficulties that led to contact with mental health services affect them day to day, and how to manage together.

- Family members should also be offered their own support. This should include information about the mental health services being used by the person they

are caring for and the conditions being treated there. It should also include support with looking after yourself as a family member. Family members may also be invited to a group.

- You may find you do not want to talk straight away when talking is offered: this is really common and the guidance for services is to keep offering. Even if talking is not offered again, do let your team or worker know if you change your mind.

Arts therapies

- These are most commonly offered while the person is in hospital, but may also be available in the community.

- Arts therapies include art, music, dance/movement, and sometimes drama. They can be offered individually or in groups.

- The idea is to help process experiences in different ways, other than by talking, although in some groups, people may also talk.

- Again, if you are not offered arts therapies, ask your team/mental health worker.

Social, occupational, vocational and leisure support

- People with psychosis often find it difficult to access social opportunities. They may feel uncomfortable contacting friends, find social situations pressured, or find their friends are doing other things, so they have gown apart. Mental health services therefore usually offer support to find social contact at a level that suits the person.

- Social contact is often linked with work, training, study, volunteering, or leisure opportunities. Again, because activity can be very difficult for people with psychosis, extra support is usually offered.

- People with psychosis often find it difficult to work, certainly full-time, but most people find something personally meaningful and rewarding that they can spend some time on. Supported employment. Part time. Less demanding roles.

- The support can also include help rebuilding, or learning afresh, daily living skills like washing and self-care, looking after clothing, cleaning, cooking, and looking after where you live. Managing money, using shops and other community facilities, and finding things to do with your time might also be

supported. These skills are often affected by an episode of psychosis or by a period of time spent in hospital.

MANAGING STRESS AND SOLVING PROBLEMS

- People with psychosis are often more sensitive than other people to some of the things happening around them, and more easily upset by life's daily hassles. It is not possible or desirable to reduce stress completely and there is a balance to be struck between getting involved in things again, or trying to solve problems, and keeping stress levels down. The balance will be different for each person. Some ways of reducing stress may be:

- Keeping close relationships and the atmosphere in the home as smooth and calm as possible

- When there are problems at home, trying to find a way to manage them calmly

- Changes in routine like new people, activities, or environments can be difficult. Knowing about these in advance and preparing can be helpful.

PLANNING AND PREPARING FOR CRISES AND RELAPSES

- Although it might well feel like the last thing you want to do, especially if things have been going well, planning for things getting difficult again can be really helpful.

- Most people do experience more than one episode of psychosis. Planning doesn't mean it will happen, but can help you all feel less worried, and, if it does happen, give you some ways to manage.

- Planning involves thinking together about what might make things difficult and what signs each of you might notice.

- It can help to look at a list or set of cards together of common signs of things getting difficult. These can include changes in mood, or behaviour, and are different for everyone.

- The signs can often be sorted into early (the very first things anybody might notice), middle, and late (the things that happen once things have got quite difficult again).

- Things that help might be reducing stress and taking things easier, looking after yourself a bit more, and thinking about how you might talk about any changes together – what is helpful and not so helpful to say.

- Letting your team know is often useful and you can discuss with them what might help. Usual responses are changing medication or seeing a person more often for extra support.

- The difference between everyday changes in mood and reactions to events and things starting to get worse can be hard to judge. It is usual to be more worried about any changes soon after an episode. Over time, as you experiences everyday changes without a relapse, this usually gets easier.

TIPS FOR FAMILIES

- It can be very difficult being in close contact with a person with psychosis

- You may feel frightened by the person's behaviour, and worried about where they are and what they are doing. Sometimes it can feel easier to keep the person always in your sight, or take over doing things for them.

- The person's behaviour, and the worry, can also make you feel angry and frustrated. You may find yourself criticising the person, or 'having a go' at them, when you just want things to be better.

- Alternatively, you may find yourself treading very carefully, and avoiding saying anything, even when you are very worried or afraid, because you are afraid of upsetting the person or provoking a reaction.

- It is normal to think about how you will manage and how things will go in the future.

- Any kind of caring can be stressful, and can have a negative effect on your physical and mental health. It is very common, for example, for people in caring roles to become depressed.

- Showing your worry or upset, or getting cross can also make things worse for the person you are caring for, as it can be hard for them to take criticism or fuss.

- Talking with others, who understand psychosis and your caregiving role, can be helpful, and this is one of the reasons services often have carers groups.

- It can also help to make sure you give each other space and time alone, and keep your own independent lives and build or keep up with social contacts, independent activities and interests.

- When you are together, try not to shout, criticise the person, or act too worried or upset. This can be very hard when things are difficult and you care for the person a lot.

- Try not to take over too many things, or overburden yourself with more tasks and responsibilities. It will be easier for both of you if you feel less stressed.

- Try not to argue a person out of a belief that you do not think is true – even if the belief upsets the person. It is usually more useful to note that you both have different views, but that you can see the person is sure. It can feel very silly acknowledging something that you know is not the case. Asking the person how they feel about the belief and how they are managing can also be helpful.

- Recovery from psychosis or contact with mental health services takes time for the whole family.

- It is common after significant life events for people to change in some way: they do not ‘go back’ to being exactly the same person they were before the experience, but instead incorporate their experiences into their life story and way of being.

- Having psychosis, and/or contact with mental health services can have a particular impact: there can be a lot to accommodate and adjust to. The same is true for people who love and care for those who have experienced psychosis.

- Although many of the changes and adjustments for the person and their family can be very difficult to manage, some of these changes can be positive, and can make people realise what is important about their lives, bring them closer, or lead to changes in their priorities.

- It is good to realise that recoveries from psychosis can go at different rates, and sometimes carers and families recover later than the person directly experiencing the psychosis.

- Mental health services are here to support you. In addition, many other families have been through similar situations. Although it may feel very lonely at times, you are not alone in having had these experiences. Please do reach out if you feel it may be helpful to you. There is a list of helpful numbers and websites below. We wish you well with your recovery.

RESOURCES

1.Mental Health Care: www.mentalhealthcare.org.uk
Website specifically aimed at carers and friends of people experiencing psychosis
2. Rethink Mental Illness: www.rethink.org
Rethink Mental Illness is a mental health charity which provides information and advice on different aspects of mental health.
Advice and information service: 0300 5000 927 (Mon-Fri: 10am-2pm).
www.rethink.org/siblings
This section of the website is designed for siblings of people who have experienced mental health problems.
3. www.futurelearn.com/admin/courses/caring-psychosis-schizophrenia. Free online course focusing on caregiving issues.
4. MIND www.mind.org.uk
Mental health charity offering help and advice to individuals experiencing mental health difficulties and their families and loved ones.
Free phone on landline: 0300 123 3393 (will use inclusive minutes from contract on mobile). Open 9am-6pm Mon-Fri.
5. SANE www.sane.org.uk
Mental health charities offering help and advice to individuals experiencing mental health difficulties and their families.
0845 767 8000 (Everyday 6pm-11pm)
Online support forum:
www.sane.org.uk/what_we_do/support/supportforum/support_rooms
6. Hearing Voices Network: www.hearing-voices.org
A national organisation providing advice and support groups for people who hear voices and their relatives. They run self-help groups for voice hearers.
Phone number: 0114 271 8210, email: nhvn@hotmail.co.uk
7. Carers UK: www.carersuk.org
Carers UK is a charity providing specialist advice and support for carers.
8. Young Minds: http://www.youngminds.org.uk/ Young Minds is the UK's leading charity committed to improving the emotional wellbeing and mental health of children and young people.
9. Health Talk Online www.healthtalkonline.org An award winning charity website that allows you to share your own and other people's experiences of health and illness. The website includes a section on the mental health experiences of ethnic minorities and depression.
http://www.healthtalk.org/peoples-experiences/mental-health/
10. Medicines www.medicines.org.uk Contains copies of public information leaflets on all medication
11. Talk To Frank www.talktofrank.com Information about street drugs.
12. The Royal College of Psychiatrists: www.rcpsych.ac.uk
The Royal College of Psychiatrists website has tailored information for service users, carers, mental health professionals and employers.
www.rcpsych.ac.uk/mentalhealthinformation.aspx

This particular section has a large range of information leaflets on mental health problems and treatments, which you can download for free.
www.rcpsych.ac.uk/mentalhealthinfo/workandmentalhealth.aspx
This section provides information, guidance and resources for people who are planning to return to work after a period of mental ill health.
13. NICE: www.nice.org.uk/guidance
The National Institute for Health & Care Excellence (NICE) provides expert guidance on all types of health care including mental health.
14. Samaritans: www.samaritans.org
The Samaritans have a confidential 24-hour phone line which is available to anyone who is in crisis or suicidal:
0845 790 9090 or free phone number: 116 123.
Useful information:
Understanding Psychosis and Schizophrenia (Division of Clinical Psychology, British Psychological Association, 2014).