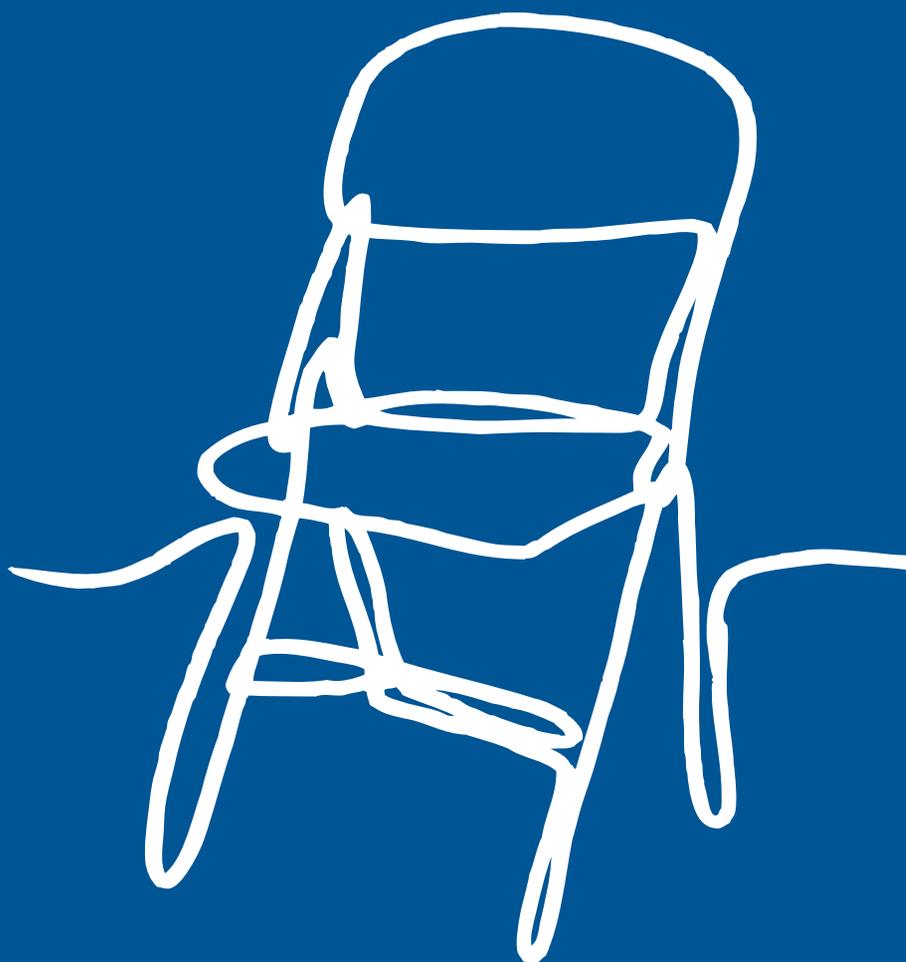


6. The mental health maze – working with mental health professionals

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Who's who?

Mental health disorders can be complicated to treat because they can impact on a wide range of issues, such as housing, employment, relationships, and physical wellbeing. As a result, there are a number of different mental health professionals, each with their own specialised expertise, who may be involved in the treatment and care of your relative, partner or friend.

If your relative is referred to a specialist mental health service they may have contact with a variety of different professionals at different times. Specialist mental health services are 'multi-disciplinary' with different professionals sharing their expertise within the team. This will mean that best practice is shared, for example, if your relative has a community psychiatric nurse as their care coordinator they can ask a social worker in their team for specialist advice and guidance about a housing issue.

Below is a brief description of the role of mental health professionals you, and your relative, may come into contact with.

Consultant psychiatrists are medically qualified doctors who specialise in mental health problems and disorders. They are responsible for the assessment and care of patients, and they are the clinical leaders for the teams they work with, which may include community mental health teams, ward teams and rehabilitation teams. Other doctors will also form part of these teams. **Specialist registrars training in psychiatry (SPRs)** are completing higher specialist training; they would have successfully completed 3 years of core training in psychiatry, and often run outpatient clinics and ward rounds on behalf of the consultant psychiatrist. Core trainees, or **Senior House**

Officers (SHOs), are qualified medical doctors completing 3 years of specialist core training in psychiatry.

Care coordinator is a named individual in a specialist mental health team who takes lead responsibility for ensuring that agreed services are provided when someone is under the Care Programme Approach (CPA). They may be a social worker, community psychiatric nurse, occupational therapist or sometimes a doctor. The care coordinator will be the main contact and support worker for someone under the CPA process, please see pages 116 - 123.

Community psychiatric nurses (CPNs) are nurses who assess people's mental health and work with people with mental health disorders and their families to plan supportive treatment in the community. They can also administer medication and provide information and/or referrals to other services and support networks locally. They can also run nurse-led clinics for clozapine and depot injections.

Social workers are likely to be involved if people are experiencing social exclusion and they have a wide working knowledge of people's legal entitlements and rights. Social workers help to provide access to services that help people deal with problems or issues that arise in their lives. Social workers promote independence, dignity, choice and self-directed support.

Occupational therapists (OTs) help people with mental health problems develop or learn the skills required for daily living – for example, this could include domestic skills (cooking or cleaning), social skills or development of a social network. Their work could also include such areas as confidence-building and promoting self-esteem; they also carry out assessments for home discharge from hospital wards.

Clinical psychologists undertake extensive and specific training in psychological functioning and development. They have a key role in assessing a person's ability to function in terms of thinking, remembering and understanding, and personality traits. They do not prescribe medication but use a range of talking treatments in a group or individual context as part of a treatment programme.

Community support workers (CSWs) provide practical help and support with daily activities. They can also support people to access social activities and they are able to visit people in their homes when an assessment has identified this as a need.

Approved mental health professionals (AMHPs) carry out specialist assessments of a person's mental health needs and whether they need to be admitted to hospital under the Mental Health Act 1983. Such assessments must be done jointly with medical professionals. If the outcome of the assessment is a recommendation for compulsory hospital admission, the AMHP can make an application for this. The AMHP also has a duty to inform or consult the nearest relative.

The Care Programme Approach (CPA)

The Care Programme Approach, or CPA, is a way of identifying important health and social care needs for someone experiencing severe mental health problems. It provides an organised way of assessing all your relative's health and social care needs, and then developing a single care plan to meet the needs identified in their assessment

The CPA:

- gives a clear framework so that every aspect of your relative's care is recorded in one place
- gets all the agencies which can help meet your relative's needs involved in a coordinated way
- creates plans for coping with aspects of your relative's care plan should a crisis arise
- recognises the role of families and friends and the support they need
- identifies needs that are not met so necessary actions can be planned.

Importantly, the CPA is also intended to make the care process better for your relative. The CPA is intended to give ownership of the care process to your relative, the service user. It should also promote fairness and equality, as well as cultural sensitivity.

The CPA can be a useful tool – the process is designed to get your relative fully involved in planning their care, with a voice in the decision-making process.

Who is the CPA for?

The CPA is for people with complex needs receiving care from specialist mental health services. Your relative will be referred for a CPA assessment by primary mental health services – usually their GP or a specialist in primary mental health services.

Assessment If it is decided that your relative might need specialist help for their mental health problems they will be assessed. This assessment is carried out to identify their needs and determine the level of support they need.

The CPA is for people who have multiple care needs, have multiple problems, or who may be a risk to themselves. Basically it is for those with a greater need of support who cannot be safely managed in primary mental health services by their GP. It means they will have a more detailed care plan which will cover many different areas of their life.

To decide whether your relative needs the CPA, the assessment will consider:

- their presenting problems
- their symptoms
- their psychiatric history
- their current medication, if any
- their physical health history
- their social care needs
- their ‘forensic’ history (whether they have a criminal record, etc).

They may also be asked about things such as whether they consume alcohol or drugs. They should have the opportunity to write their comments on the assessment form. Once they have signed it, a copy of the summary will be given to them and a copy will go to their GP.

If it is decided that your relative needs to be cared for under the CPA, they will be allocated a **care coordinator**. This is a health or social care professional who the care team think would be the best person to oversee your relative’s care. For example, it could be a social worker or community nurse – the team will assess who is going to be the best person to work with your relative.

Your relative may well have further assessments that are more in-depth at this stage to assess all their health and social care needs and you will be offered a ‘carer’s assessment’ in order to inform the assessment process.

Your relative’s social care needs will be assessed using guidance from the Fair Access to Care Services (FACS) eligibility criteria and they may be entitled to financial support for their social care needs through something called ‘self-directed support.’ For more information please ask your relative’s care coordinator or a carer support worker.

Try to make sure your relative is comfortable with their care coordinator as they will work closely with this person on their care plan. For instance, they might prefer someone who can respond to any specific cultural or gender needs. They can ask for a change of care coordinator if they do not meet their needs. This may not always be possible but it is always worth making a request.

What will your relative's care coordinator do?

The care coordinator will be the point of contact for your relative, their family and all professionals involved in their care plan.

The care coordinator will complete the care plan with them and review it with them, and they will oversee their care process and the assessment of their needs. If they go into hospital, the care coordinator will remain in contact.

The care coordinator will also:

Make sure the appropriate people, such as health professionals working with your relative on the care plan, get a copy of the plan

Be involved in the admission and discharge process if they go into hospital

Complete a risk assessment

Organise the assessment of your needs – this is called a carer's assessment, see page 123

Arrange meetings to review the care your relative is getting

What's in my relative's care plan?

A care plan is usually a couple of pages long with a variety of boxes or sections to be filled in. The plan will usually have space to include:

A list of their care needs – including housing, employment, training, benefits, etc

A list of goals and objectives matching the needs they have identified

Recovery goals your relative has identified

Plans for which services will help your relative with these goals

Plans for what actions are to be taken and by whom

A space to list strengths, ie things your relative doesn't need help with or that they can build on

A timetable for meeting the goals and objectives.

There should also be:

Space for your relative and others to make comments – try to make the most of this and support your relative to have their opinions or aims written down if applicable, including any objections they may have to their care plan

A contingency or crisis plan including lists of contacts and points of action to be taken should a crisis arise

A date for the next review that everyone agrees to

A place for signatures so your relative and their care coordinator can sign when they have agreed the care plan.

How to help make your relative's care plan work

The CPA is designed to meet a wide range of needs. Before your relative starts to develop their care plan they can look at the key areas of their life listed below and think about what they may want to achieve.

Try to ensure that all of these areas, and anything else that matters to them, and to you, are covered in the care plan. It can be helpful to make a note of what your relative and you want to achieve before you go into a meeting, or simply underline any of the statements on these pages that are relevant and take this guide with you. Not all of these statements will apply to your relative but they might help to identify different areas for discussion during the meeting.

Your relative should be involved in writing and agreeing the care plan as much as possible. Try to insist on this.

If you or your relative find reading and writing difficult, or if their first language is not English, it is important to make sure the care plan is provided to your relative in a way you can all understand fully.

Medication

(Please Note: your relative should always consult their doctor before changing their medication regime.)

- Find out about the latest medical treatments for their diagnosed disorder
- Ask the doctor to prescribe a more appropriate medication for them as an individual
- Find out about side effects and how to reduce any unpleasant ones
- Find out about management requirements of their medication and talk to their doctor or nurse about these
- Ask about a second opinion if they disagree with their diagnosis or treatment plan
- Take the right amount of medication which has the most benefit for them with their doctor's advice.

Other Treatment and Therapies for Mental Health Disorders

- Find out about the range of non-medical therapies and treatments recommended for their diagnosed disorders
- Ask about Cognitive Behavioural Therapy – CBT
- Ask about other psychotherapy/talking therapies
- Find out about other therapies, eg art therapy and mindfulness
- Explore alternative therapies, eg acupuncture and massage
- Learn more about their mental health problems and self-management techniques
- Find out about courses available through The Recovery College
- Find out information about local self-help groups, eg Hearing Voices Group.

Physical Health

- Make sure they are registered with a local GP
- Get information about physical health checks that they need, eg blood tests
- Take care of their physical health – paying attention to their diet, smoking and drinking
- Help with problems related to taking illegal or street drugs
- Go to the dentist for regular check-ups/find a suitable dentist
- Go to the optician
- Take some regular exercise – regular walking, joining a gym or playing sport, eg football, badminton
- Attend ‘well man’ or ‘well woman’ clinics.

Accommodation

- Manage their own accommodation
- Share a home with family or friends
- Live in their own home with support
- Live in shared accommodation with support
- Stay in specialist 24-hour supported accommodation.

Money

- Earn a salary or wage
- Apply for a student grant or loan
- Maximise their social security, disability or other benefits
- Enhance their budgeting skills
- Get information and/or support about debt or savings management.

Social life, spiritual life and leisure activities

- Maintain relationships with their family
- Maintain relationships with their friends
- Live in a personal relationship with a partner
- Engage with a religion or tradition of their choice
- Be supported while using general leisure facilities
- Use specialist supported leisure facilities

- Follow their hobbies or interests individually or in a group
- Take up a new interest
- Find new opportunities to meet people.

Training and education

- Study in full-time, or part-time, education
- Get financial support to maintain them in training or education
- Use distance learning packages, eg Open University
- Follow work-related or interest-related adult education courses
- Take up self-study through reading, Internet, etc.

Employment

- Work full-time, or part-time, in general employment
- Get specialist support to maintain them in general employment
- Use a specialist supported employment service to find employment
- Use occupational therapy services
- Study/train for employment
- Become a volunteer.

Parenting

If your relative has parenting responsibilities they will probably need to discuss this during their CPA meeting. They might need additional support and they will probably need to plan for what they would like to happen should they experience a crisis.

Contingency and crisis planning

There should be a section in your relative’s care plan for ‘contingency/crisis planning’. It is a space where information can be recorded which will be useful should a crisis occur.

Contingency planning is planning ahead for certain situations, for example, when your care

coordinator is not available. This plan would include a record of useful numbers of service providers who can support your relative during this time.

Crisis planning is planning ahead in case a crisis takes place – times when your relative might be very ill. Crisis plans should set out the actions to be taken if your relative's mental health deteriorates rapidly. These plans should be agreed with your relative and if appropriate with you as well.

Crisis planning is useful as it means that all involved can agree beforehand on what happens should a crisis happen. We advise that an advance statement is drawn up between your relative, you and the care coordinator and others involved so that if a crisis arises, it is dealt with properly and in the way that both you and your relative would like.

What's in a crisis plan?

A crisis plan should include:

Possible early warning signs of a crisis and coping strategies

Support available to help prevent hospitalisation

Practical needs if they were to be admitted to hospital, eg childcare or the care of other dependants, including pets

Details of any advance statements

The degree to which families or carers are involved

Information about 24-hour access to services

Named contacts including who to contact if their care coordinator is not available.

Risk assessment

Your relative will have a risk assessment form completed when they take part in the CPA. This will contain an assessment of what risk they might pose to themselves or others. For example, through self-harm, suicide, violence, self-neglect, exploitation or criminal activity.

The risk assessment form should record any degree of risk indicated:

- by you
- by your relative
- by their recent behaviour
- by their current mental health
- by their current circumstances.

Please see pages 131 - 133 for more information on *Talking to professionals about risk*.

Reviewing your relative's progress

Once your relative's care needs have been agreed on their care plan, the care coordinator will oversee the care process. All the relevant agencies will now need to deliver the services that meet your needs.

CPA Review

Your relative will have a care plan review at least every twelve months but if they need to, they may have reviews more frequently.

The care coordinator should also review and evaluate the care plan continuously through their contact with your relative. The formal review, however, is the best opportunity for your relative, you and their care providers to have a say and reach agreement.

Ask for regular reviews. Reviews are essential – for one thing, they provide an opportunity for everyone to set short steps toward long-term goals and monitor them regularly.

It is important that these short steps are timetabled and that your relative has regular reviews to assess their progress toward them, or even to make changes if necessary.

At a formal review, a CPA review form must be filled in. On the review form your relative should have the opportunity to put down their view about their needs and how services are meeting these, as will the professionals. You will also have space to do this if your relative gives their permission.

The form will describe any changes in your relative's circumstances since the last review

and assess whether the care plan is working. It will also record unmet needs along with the actions that need to be taken to meet them. If your relative does not want to address an unmet care need it may be difficult for both their care coordinator and yourself to address the need until they are ready.

It also may not be possible for the care team to address all unmet needs as the appropriate services may not be available locally. If you have identified a gap in local services that you would like addressed you can contact your local carer support services and ask them to raise this for you. You can also become involved in developing local services by taking part in local consultations and joining strategic groups. Your local carer support services can give you more information about how to do this, see page 137 for more details.

At the end of the meeting the care coordinator will make a recommendation to continue with the care plan as it is, or to amend it. If your relative agrees with this they may also sign the form. There may be parts of the form that your relative disagrees with and their care coordinator should note these disagreements on the form.

Emergency CPA reviews may sometimes be required, for instance if a crisis arises. You, your relative, or anyone in your relative's care team can initiate this. You need to contact your relative's care coordinator to do this. If they are not available, you can ask to speak to the team manager.

Carer's assessments

If your relative, partner or friend has mental health problems and you are providing a significant amount of support, or your role is having a negative impact on your own health and wellbeing, you are legally entitled to something called a 'carers assessment'. This involves meeting a professional so you have the opportunity to discuss in confidence the impact your role is having on you without the fear of upsetting your relative.

This is an opportunity to get advice and guidance about the help and support you may need to continue with your valuable role. It can also be a valuable opportunity to communicate with the care team working with your relative, partner or friend so they are aware of your circumstances and concerns.

Why am I called a 'carer?'

You are a carer:

- If you support a relative, partner or friend who needs support in their own right because of mental health problems
- If you are not receiving any payment for the care you provide (excluding any state benefits you may receive due to your caring role)
- Regardless of your age – you may be under 18 years of age and caring for a parent or relative with mental health problems
- Whether or not you live in the same house or area as the person you care for
- Regardless of whether you provide full-time or part-time support to the person you support

- Whether you are the only person looking after the person you care for, or one of a number of people, both professional and non-professional.

Someone who provides unpaid practical or emotional support to a person with an illness or disability is known as a carer. When this term is used, it is talking about relatives, partners or friends supporting someone with a disability.

You're a carer, whatever your age, if you provide unpaid help to a partner, child, relative, friend or neighbour, who couldn't manage without you. This could be due to age, physical or mental illness, addiction or disability.

'Carer' is a government term used in legislation and guidance and, as such, health and social services are required to use it.

What am I being assessed for?

The purpose of the carer's assessment is to identify what needs you may have in your own right.

Sometimes families are concerned they are being assessed for how well they provide support, or that they may be expected to take on additional responsibilities if they are formally recognised as a carer. The carer's assessment is not used for either of these purposes; the purpose of the carer's assessment is to identify what needs you may have in your own right.

This is an opportunity for you to identify any roles that you no longer wish to continue or feel unable to continue and to discuss any problems or issues that are created by your supporting role. For example, this is an ideal opportunity to raise any concerns you may

have about confidentiality or your involvement in care planning for your relative.

Why should I be interested in a carer's assessment?

You are very important in helping to provide support to your relative. As such, you are entitled to the support you need to help you continue in that role and to maintain your own health and wellbeing.

Local health services and the local authority are committed to the principle that you should be recognised as a key member of the team looking after the person you care for. Carer's assessments are the process whereby they can ensure that carers who provide a substantial amount of care get the support they need to maintain their own health and wellbeing.

What if the person I am supporting is not being treated by specialist mental health services?

You are still eligible for a carer's assessment if your supporting role is having an impact on your own health and wellbeing. Contact carer support services to find out how to access a carer's assessment.

What help might you need?

While many people find their role extremely rewarding, supporting someone with a mental health problem can be very distressing and exhausting. It can sometimes leave you feeling alone and with little time and energy to do anything else. Things that might help:

- You may want an opportunity to just discuss your situation, or get advice and information about the disorder and possible treatments for your relative

- You may want some advice on responding to difficult behaviour symptoms
- You may want some emotional support and a chance to talk to other people who are supporting someone with mental health problems
- You may want to have a holiday or take a break from your caring responsibilities
- You may want advice about whether or not you're getting all the financial and practical help you can
- You may want someone to support you at a meeting to discuss how the person you are caring for is being treated and looked after.

How do you get the help you need?

During the carer's assessment meeting you can talk about the impact caring is having on your life and discuss what might assist you in your role. The meeting should help by:

- Clarifying the kinds of help and assistance you might need
- Working out a plan to ensure you are getting the best help and support that is available
- Reviewing that plan periodically to see if it has helped, and if not why not.

The process is about helping to support you, not assessing your ability.

What does a carer's assessment involve?

The process involves meeting with a mental health professional or community support

worker to talk about your situation and to agree what support you need and how you will get it. The meeting will also establish whether your circumstances, or those of the person you care for, have changed.

What is agreed is then recorded in a short written Carer Support Plan which you will be given a copy of. None of the information you share will be given to the person you support unless you give your permission.

You can also ask a friend or advocate to be present at the meeting if this would help. If you have trouble understanding English or need help to communicate because, for example, you have sight or hearing loss, you can request to have an interpreter present. The person who is meeting with you will be able to arrange this.

How long will the process take?

The process itself will require at least one initial meeting to discuss your situation. These meetings usually last about an hour but can take longer depending on your personal circumstances. It may be that you need more than one initial meeting to agree the support plan, as it may take some time to develop confidence in the person who is meeting you. Your carer's assessment will then be followed by annual review meetings.

If you have family or work commitments that make meeting during normal office hours difficult, you are entitled to ask to meet out of hours and teams will try to accommodate this if they can. If this is not possible, you will have the opportunity to talk by telephone. You are also entitled to ask for meetings in your own home if this would assist you.

When does the process begin?

You will be offered a carer's assessment at the point that you, or the person you support, first comes into contact with specialist mental health services. If it has not been offered, you can request a carer's assessment and the care team will arrange a meeting with you.

A carer's assessment is part of the Care Programme Approach (CPA). The carer's assessment is carried out in order to make sure that your situation is taken into account when plans are being made for the treatment and care of the person you are supporting. The CPA also helps to make sure your carer's assessment is reviewed every year.

If you would like a review before it has been offered because your circumstances have changed and you are finding it difficult to cope, then you should contact the care coordinator or carer support service to arrange this.

Who will be involved in the process?

The care coordinator responsible for your relative's care or a community support worker will be responsible for holding your carer's assessment meeting. They will already have some understanding of the situation and will be able to take this into account when considering with you what might help.

However, you may prefer your assistance to be provided by someone who is not directly involved with your relative or your relative may request this. In these circumstances the care coordinator will find another member of the team, or an independent community support worker to talk to you.

How will any personal information be protected?

When your support plan is completed, records will be stored in a separate section of the file relating to your relative.

All records are confidential and will not be passed on to people outside the team working with your friend or relative except in very specific circumstances or unless you give your permission. If you have requested a small carers payment from the local authority your carer's assessment will be recorded on the local authority's secure database in order to authorise the payment.

No information will be shared with your relative unless you give permission for this.

If you are asked any questions that you feel are too intrusive, you do not have to answer them. You should only give information that you are comfortable sharing.

Confidentiality

It will be very important for your relative to feel able to speak freely with professionals. People with mental health problems often share very difficult and intimate thoughts and feelings with the professionals who are treating them. If they are sharing very personal information with a professional, they might be concerned about anyone else finding out.

Aside from the legal constraints of sharing information without consent, professionals will also be concerned about damaging their therapeutic relationship with your relative. It will be important for your relative to build trusting relationships with the professionals who are working with them – your relative's trust could be jeopardised if they thought professionals shared personal and sensitive information without permission.

Giving information You may wish to provide information you believe would be helpful for treatment or which might prevent a worsening of your relative's condition. Or you may wish to offer care or seek advice to help you to cope better with the impact of the disorder on yourself or other members of your family and friends. It can be difficult to know what to do if you have little basic knowledge about the disorder, or don't know how best to deal with difficult behaviour symptoms. If your relative expressly forbids them from contacting you, mental health professionals often find it difficult to decide whether to breach confidentiality. The first thing for families and friends to know about confidentiality is that even if your relative has requested no information be shared with you, **nobody can prevent you from giving information to professionals.**

If a professional refuses to allow you to give them information on the grounds of

confidentiality, they are mistaken in their understanding of confidentiality and you can challenge this decision. If you require support in this you can contact your local carer support services.

Why do professionals not share information with me? When you are looking after someone, you may feel you have a right to access information held about them, or that you need information about them to help you support them. However, the law makes it very clear that social services and healthcare services have a legal duty to protect an individual's confidentiality. Confidentiality is protected through human rights law, common law and professional codes of conduct. It is important to understand that you don't have an automatic right to personal information about your relative.

Get early agreement A lot can be achieved in avoiding later dilemmas by setting out an agreement about confidentiality at the earliest possible stage with the care team and your relative. This is best done when your relative is reasonably well and able to participate with you and the care team in a meeting, spelling out the circumstances under which discussions with you can take place, and what information can be exchanged. Their consent can then be recorded on their case notes and there should be no further problems unless your relative changes this decision.

For example, there might be agreement that if your relative shows particular early warning signs of a crisis, the care team can discuss this with you in order to reduce the likelihood of the crisis further worsening. It could also be agreed what help you might require from the care team on an ongoing basis in order to cope better with your relative's mental health problems.

It is important to understand that people can change their minds about sharing information and that professionals have a duty to respect your relative's wishes. If you have noticed a pattern where your relative is happy for you to be included until they experience a crisis and at that point they change their mind, it would be helpful to look at setting up an 'advance statement' if possible, see below.

What if my relative refuses to give permission?

At this point you will need to think quite clearly about exactly what information you would like and why you would like it. You can then give this list to your relative and the professional working with your relative. Professionals can then discuss your request with your relative and they may agree to you being given the specific information you have requested.

One of the problems with giving consent to share information is that it can tend to operate as a very basic on/off switch. While your relative may not be prepared for you to have access to personally sensitive information, they may be prepared for you to have other information; for example, details of any side effects of their medication.

If you have made a list of the information you would like and why, but your relative still refuses to give permission to share information, this should be revisited by professionals on a regular basis – especially if you are providing regular and substantial support or you are living with your relative. They should talk to your relative about any concerns they may have about you having information – it may be possible to ease your relative's concerns and/or help them to understand the value of you having certain information.

If this is causing you problems it can also help to request a carer's assessment if you have not already had one – there is nothing to stop professionals looking at your support needs independently of your relative's care. This is also an opportunity for you to highlight the difficulties you may be experiencing without information.

Learn how to discuss disclosure It is important to learn how to discuss giving information or 'disclosure,' against your relative's wishes when it might be in their 'best interests.' There are no fixed rules about the seriousness of the harm that justifies disclosing information against someone's wishes. Families can help mental health professionals think through the issues at stake.

Advance statements Families often find that they only experience problems with confidentiality when their relative is in a crisis. Sometimes the person with mental health problems is surprised that nothing was shared with their family when the crisis has passed and they would have liked their family to have been kept informed. The best way to prevent this from happening is for your relative to make an advance statement.

This is a formal record of what your relative would like to happen should they experience a crisis. In their statement they can clearly outline who they would, and wouldn't, like information shared with. Their advance statement would then be placed on their clinical notes and decisions to share information would be decided by what your relative expressed in their statement when they were well.

They may share their advance statement with you and they can also give you a copy for your records. Sometimes, if appropriate,

families work on an advance statement together. Advance statements need to be agreed by professionals. If your relative has identified a role for you in their advance statement, they need to check with you first that you are happy to take on this role!

General information Even if your relative has made it clear they do not want any information shared, this does not mean that professionals cannot talk to you or give you general information. The care team may decide it would be better for you to speak to someone not directly involved in your relative's care if they are worried about damaging your relative's relationship with their services.

You can be given general advice and guidance by someone not connected to your relative's care and alternative methods of support for you can be explored. You can gather a lot of information that will be helpful for you without it being personal information. Here are some examples of general questions you could ask:

What do I do if there is a crisis? Who do I contact? What might the warning signs of a crisis look like?

How do I respond to a behaviour symptom that I am finding really difficult?

What would the treatment be for someone who was suffering from depression?

My relative hasn't eaten for two weeks and I don't know what to do. What is the best way to manage this?

Mental capacity Does your relative have the 'capacity' to make treatment choices? Family involvement can be seen to be a 'treatment

choice.' Capacity involves a person's ability to:

- understand the nature of the treatment being offered including the likely consequences of having or not having that treatment
- appreciate that they suffer from a disorder (or at least a problem affecting their mental health) requiring treatment or special help
- reason with the information they now have about their disorder and treatment.

If your relative has serious difficulty with any of these, they could be regarded as lacking capacity. If this is the case, you might want to discuss the following with professionals to guide them in deciding whether maintaining confidentiality is in your relative's best interests.

What is the seriousness of the harm faced by your relative and the probability of it occurring? What is the risk?

Are there alternatives available that might reduce the likelihood of harm?

How would contact with you or another family member or friend against your relative's wishes be likely to be received by your relative? For example, a close family with good relationships but which the patient, as the result of a psychotic disorder, sees as 'rejecting' them might be regarded differently compared to a family with long-standing disharmony. There might have been previous discussion with the patient implying that contact would be acceptable under the current circumstances



It might also be asked whether the patient, following recovery, would be likely to see family involvement as having been desirable after all

Is the principle of the 'least restrictive alternative' relevant? In other words, will your involvement reduce the likelihood of even greater restrictions on your relative's freedom becoming necessary, eg later involvement in treatment resulting in an admission to hospital? This principle is implied in certain circumstances, as in the requirement to consult the nearest relative before compelling admission under some sections of the Mental Health Act 1983.

By talking through these issues with the care team, reasons for breaching or not breaching confidentiality should become clearer to all.

Need to know/risk Professionals need to ensure a careful consideration of the potential impact of sharing information on both their client and the people who are supporting them, this then underpins any decision to share information. Sometimes there may be a potential risk to the patient, another person, or their family if information is not shared. If a potential risk can be clearly demonstrated the professional can share information on a need to know basis. This would need to be a shared decision within the team and recorded on your relative's notes.

Your rights to confidentiality You also have the right for information you share with professionals to be kept confidential. Best practice generally recommends that it is better if everybody is able to share information, but

there may be particular occasions when you do not want certain information to be shared with your relative.

The only time you cannot have confidentiality is during a mental health tribunal. This is worth bearing in mind if you are submitting evidence to a tribunal.

You may find that different professionals are more confident about working with families and confidentiality than others. Often more experienced professionals, or those who have been specifically trained to work with families, are more confident in overcoming the barriers created by confidentiality. If you are not happy with how your concerns are being responded to, ask to speak to the team manager or someone who has been specifically trained to work with families.

Talking about risk

It can help when you are talking to professionals about risk if you have a better understanding of how professionals are likely to be considering risk for your relative. Professionals will probably use an approach called 'positive risk management'.

Positive risk management means being aware that risk can never be completely eliminated, and that care plans inevitably have to include decisions that carry some risk. This should be very clear in the decision-making process and should be discussed openly with your relative and yourself.

Another way of thinking about good decision-making is to see it as 'supported' decision-making.

Good approaches to choice and risk are based on people having the right to live their lives to the full as long as that does not stop others from doing the same. Fear of supporting people to take reasonable risks in their daily lives can prevent them from doing the things that most people take for granted.

What needs to be considered is the consequence of an action and the likelihood of any harm from it. By taking account of the benefits in terms of independence, well-being and choice, it should be possible for your relative to have a support plan which enables them to manage identified risks and to live their life in ways which suit them.

Risk management works best when someone's strengths are recognised alongside the possible problems that they might encounter. Every time a problem is identified, a strategy should be suggested and discussed, building on the positive skills of your relative. The

Positive risk management includes:

Working with your relative to identify what is likely to work

Paying attention to your views and those of others around your relative when deciding a plan of action

Weighing up the potential benefits and harms of choosing one action over another

Being willing to take a decision that involves an element of risk because the potential positive benefits outweigh the risk

Being clear to all involved about the potential benefits and the potential risks

Developing plans and actions that support the potential benefits and priorities stated by your relative, and minimise the risks to them or others

Ensuring that you, your relative and others who might be affected are fully informed of each decision, the reasons for it and the associated plans

Using available resources and support to achieve a balance between focusing on achieving the desired outcomes and minimising the potential harmful outcome.

emphasis should always be on a recovery approach and on the next stage in developing your relative's ability to cope when they are feeling vulnerable or having difficult demands placed on them.

It is important to be clear about the basic ideas underpinning the notion of risk. Risk relates to a negative event (ie violence, self-harm/ suicide or self-neglect) and covers a number of aspects. Try to think about:

- How likely the event is to occur
- How soon may it occur
- How severe the outcome will be if it does occur.

Risk assessment involves working with your relative to help estimate each of these aspects. Several pieces of information could be relevant. These may include:

- your relative's history of violence, self-harm or self-neglect
- their relationships and any recent losses or problems
- employment and any recent difficulties with this
- housing issues
- their family circumstances and the support that's available
- their more general social contacts.

Identifying possible triggers that have had an impact in the past is an important part of this process. Families can play an invaluable role in this process as you will have a long-term knowledge of your relative's history of mental health problems. It can be very helpful to write down a short summary of what has happened and when, so this can be shared with professionals.

Risk management and the Care Programme Approach

Risk management is part of the Care Programme Approach (CPA) and should be aligned closely with it. The CPA involves identifying specific actions based on an

individual's support needs, taking into account safety and risk issues. Care plans should be drawn up to meet all of your relative's needs, including those relating to risk.

The CPA should be applied in cases where there is an increased risk, related to mental health problems, of someone harming themselves or others. These steps help support the continuity of care, which is essential for effective risk management.

Risk management and the Mental Health Act 1983

Given the nature of mental health problems, there may be occasions when services have to intervene without your relative's consent. The Mental Health Act 1983 is used to manage a risk of harm to self and others. It should always be seen as a last resort and it is important that people who need to be treated under conditions of compulsion get the help that they need.

Using the Mental Health Act 1983 does not remove the need for discussion with your relative – it is still necessary to maximise their power to control their own life as much as possible within the restrictions of the act.

Sharing decision-making

Each step in the process of developing a risk management plan should be based on discussions between your relative and those involved in their care. Your relative should be offered the opportunity to take a lead role in identifying the risks from their point of view, drawing up plans for dealing with difficult situations, and indicating the sort of support that they would prefer. This is important because people with mental health problems and their family are often in the best position

to comment on the robustness and practicality of the plan.

The plan should include a negotiated advance statement, see page 128, giving information about early warning signs of a relapse, as well as preferred early interventions at times of crisis.

Collaborative working with carers, families and friends

You are a vital source of support to your relative and may also be a key person in helping to manage the risks identified.

Professionals need to be sensitive to the relationship between you and your relative, as there may be risks within this relationship and different points of view about the best actions to be taken. If you are at risk, you should

be seen individually so that the risks can be explored and actions can be agreed.

You should receive enough information in a way you understand to enable you to provide the necessary care. Your worries about your relative should always be taken seriously, even if the care team is less concerned.

If your relative, partner or friend is under the CPA you should be offered a carer's assessment as part of their detailed assessment and you should be helped to develop a basic plan for meeting your own specific needs. You should then be offered a review of your needs every twelve months. You can request a review at any point should your circumstances change or you feel that this is necessary due to changes in potential risk.

Working with professionals

The relationship you establish with mental health professionals involved in your relative's care and treatment is important. Giving some thought to how you work with professionals can have a significant impact on the way they respond to you. These suggestions may seem obvious, but in the middle of a crisis or a difficult situation they can easily be forgotten.

Try to remember not to base your evaluation of a service, team or hospital on one interaction or incident. Many factors can effect a professionals availability and sensitivity on a particular occasion. Furthermore, you may have more in common with the staff than you may think. They want what is best for your relative, even though you may not agree with them on what that is.

Professionals may be feeling just as frustrated, angered, and saddened by the mental health situation in this country as you are. By viewing them as allies, your relationship with them will probably be much more satisfying.

To enhance your relationship with professionals and service providers, try to:

Try to keep in mind the frustrations and constraints professionals also face, such as:

Be courteous. Use courtesy to your advantage as a consumer and as an advocate for your relative

Expect to be treated respectfully and with consideration in return

Provide all necessary information

Be respectful of their time

Ask how you can be involved in a supportive way

Request meetings, with or without your relative present, when you feel the need. You may also ask for your relative's diagnosis, treatment plan, medication information and prognosis (though your relative's consent will be required).

Their inability to help patients who will not accept treatment

The stigma, prejudice, and ignorance regarding mental health problems they and their clients may face

The desire of families at times for unrealistic results (cures)

Patients who do not improve because of medical science's limited knowledge regarding the treatment of people with mental disorders

The available funding for programmes/ projects and staff

Laws regarding confidentiality.

Further tips that may be helpful:

Use the communication skills from Part 5 of this handbook! Being able to give information that is precise, clear and unemotional will greatly increase your chances of being heard by a busy professional. Negotiate the best form of ongoing communication for you both – it could be email, letter or phone.

If someone uses a word or a phrase you don't understand – ask them to explain what they are talking about. Professionals can unintentionally use language that means nothing to someone who doesn't work in mental health services. Let them know that you don't know what they are talking about and ask them to use words and phrases you can understand.

Try to respect that professionals cannot necessarily 'make your relative better' They can provide the best care and treatment to support your relative's recovery, but they cannot necessarily 'make them better' any more than you can.

Respect that they may be placed in a very difficult position if your relative has requested full confidentiality They may be finding it difficult to build a trusting relationship with your relative – this will be a very important goal for them if they are going to be able to work effectively with your relative.

If you are not happy with how a member of the team has dealt with your concerns, ask to speak to the team manager Not all professionals are specifically trained to work with families and in the past families were not included in adult mental health care. Team managers are experienced in working with families and should be able to listen to your concerns and respond accordingly.

If you feel you are not being heard, you can ask your local carers service for informal advocacy. This can sometimes be a very effective short-term solution until relationships with the care team improve.

Compliments and complaints

Services value feedback from people who use them.

- It is really helpful for services to know when they have done something well as this information can be used to support services in developing most effectively
- If something has gone wrong it is important that this information is shared in order to improve the service and to prevent it from happening again.

If you have raised a concern informally by talking to a member of the team or their manager and this has not been responded to, or you are unhappy with the response you received, you have the right to make a formal complaint. You do not have to speak to a member of the team or their manager before making a formal complaint though this can clarify whether there has been a simple misunderstanding and can be less stressful for you.

All services have a formal complaints procedure which can be accessed from their website. If you do not have access to the Internet you can telephone the service you wish to complain about for information about their complaints procedure. If you would find this difficult, you can contact your carer support service for the relevant information.

You may like support in making a complaint.

Voluntary sector organisations such as the Citizens Advice Bureau and carer support services are independent from health and social care services and they can support you in making a complaint. If you would like support in making a complaint about a voluntary sector service you can contact the

local authority to ask them for advice and guidance about who to contact.

If you are making a complaint on behalf of your relative then it is best if you can include their written permission to complain on their behalf. If written permission is not given, the person investigating the complaint will not be able to give you any information that might be viewed as confidential.

Richmond Patient Advice and Liaison Service (PALS)

Richmond PALS can help if you have a compliment, question or concern about health services. Please see page 145.

Getting involved

The Richmond Clinical Commissioning Group (CCG) and the London Borough of Richmond upon Thames (LBRuT) are responsible for commissioning local mental health and social care services for people with mental health problems.

Commissioning is the process where priorities are identified, money is allocated and service providers are chosen to deliver services. Richmond CCG and LBRuT also commission services for the people who are supporting someone with mental health problems – carers, families and friends.

Richmond CCG and LBRuT work with the organisations who deliver mental health services in the borough such as South West London and St George's NHS Mental Health Trust, East London NHS Foundation Trust, Richmond Borough Mind and other private and voluntary sector organisations. An important part of their role is to monitor the quality of local services.

They aim to ensure that the best services possible are delivered within the available resources.

If you use local services, or you support someone who uses local mental health services

- you have an expert 'lived' experience of how services work,
- and
- commissioners and services providers would like you to be involved in shaping services.

Carer support services aim to provide carers with a platform to make their voices heard on an individual and collective basis and to use their experiences to help improve the services that are available to them and to the people they care for. They can help you to access the opportunities that are available locally.

There are a range of different ways you can become involved and the best opportunities for you will be the opportunities that you feel most comfortable with. If you are interested in becoming involved you can discuss this with a carer support worker.

The kind of involvement opportunities that may be available include:

- attending regular meetings – mainly professionals involved
- attending regular meetings – carers & professionals involved
- attending regular meetings – mainly carers involved
- attending a forum with carers and service users
- attending a one-off workshop or focus group
- answering a survey/questionnaire
- co-facilitating training for carers and/or professionals
- interviewing and selecting professionals by sitting on an interview recruitment panel
- 'telling my story' as part of a training or awareness raising event.

Sometimes families and friends, who have reached a certain point in their own recovery journey are interested in supporting other families who may be struggling with what is happening. By sharing your journey and the learning you have gathered along the way, you can offer the hope and encouragement to others that can only come through lived experience. If you are interested in becoming involved in this kind of work please contact your local carer support service.