

# Information for Carers

## How Carers can Help

As an informal carer you have a vital role in reducing the impact that a diagnosis of severe mental illness has on your relative and the family in general.

Some families have found the following methods can help...

- by learning how best to support your relative as they learn to manage the symptoms of their illness, **the informal carer can promote recovery**
- by seeking information about treatment and care and developing strategies for working with the medical and mental health teams, **the informal carer can enhance the continuity of care**
- by raising issues, alerting the care teams to new problems and suggesting possible solutions, **the carer can reduce the risk of crises**
- by being assertive, challenging decisions or making complaints where appropriate, perhaps with the support of advice or advocacy workers, **the carer can get proper access to services and improve the quality of what is available**
- by participating in local consultations about services, **the informal carer can contribute to the development of new services and help maintain the existing ones under threat**
- by contacting the Healthcare Commission when it carries out inspections of local Trust's, **the carer can alert the inspectors to issues which should be investigated**
- by writing to local councillors and MPs with accurate descriptions of inadequacies within the system, **it may be possible to encourage changes of law and practice in the future.**

# Encouraging Treatment

For those who have been diagnosed with a severe mental illness, taking tablets or receiving regular depot injections over long time periods has been shown to be an effective way of preventing deterioration and promoting recovery.

However as with all medications, not everyone who is prescribed a treatment will take it as required (the right dosages at the right times) for a number of different reasons, some intentionally and some not so. This is discussed in terms of treatment compliance.

When it comes to the treatments for mental illness there are a number of common reasons why someone might not be taking their medication correctly, or even at all.

- medications for mental illness can sometimes have unpleasant side effects, and so your relative may reject the treatment if they decide the side effects of the medication are worse than the symptoms of the mental illness they have experienced
- some people during illness can start to believe that the 'strange' feelings they are experiencing are a result of the drugs and not of the illness
- some people stop taking their medication as soon as they start to feel better

Unfortunately stopping treatment abruptly often results in someone experiencing a relapse - even when they may have stopped taking their medication because they were feeling better.

## What can carers do?

Informal carers are often amongst the first to notice when a relative is not complying with their treatment, and so being aware of what you can do to help and what action to take, could make the difference between someone relapsing or not.

- if your relative has stopped taking medication or is preparing to do so, alert them to the possible problems, in particular the risks to them of having another acute episode
- if you have a good relationship with your relative's care-coordinator (key worker) let them know what is happening

- if your relative does not have a care coordinator or psychiatrist, try to talk with them about what promotes recovery and what else can be done to try to support them more in continuing their medication
- if your relative objects, and talks about troublesome side effects that are making them feel bad, explain that their medication can be reviewed and possibly even changed to one that will have fewer side effects for them
- most important of all, reassure them that by taking a responsible approach to their medication, they are gaining much-needed control over their illness - and that with time and continued good progress the medical team may eventually feel able to consider a gradual reduction or perhaps even to stop the treatment completely, at the right time
- looking into options for talking therapies alongside drug treatment may be a way for your relative to help reduce the levels of medication they are on, whilst still effectively treating and managing their condition without risking recovery

In particular instances where complying with treatment is especially problematic for your relative, you could look into whether it is possible for them to go through 'compliance therapy' which is where professionals use set techniques to address individual issues that are holding people back from being comfortable in taking their medication.

## Engaging with Support Services for your Relatives

**The government has recognised that the provision of care should be integrated to ensure that all the persons needs in relation to medical care, social support, housing, occupation and finances can be addressed together and regularly reviewed as the situation changes. It acknowledges that people have varying needs and that support required may become more or less intensive over time.**

The move away from institutional care and towards care in the community has meant that increasingly, health and social care is provided jointly by the two services (the local Health Authority and Social Services Department) working together to provide a package of care. In some cases other agencies such as the probation service or local housing department will also be involved.

## Who provides Services?

Health and local authorities have developed their joint working relationship through Community Mental Health Teams (CMHTs) These may involve psychiatrists, clinical psychologists, Community Psychiatric Nurses (CPNs), social workers occupational therapists and others who develop a Care Plan for the person using services. The local GP should also be involved.

The care plan should identify the needs of your relative and make arrangements for meeting them. There is a requirement that a key worker / care coordinator should be named in the care plan.

### **Care Co-ordinator**

This person acts as a link between the team and the person for whom they are caring and where possible for the informal carer.

The care co-ordinator is therefore likely to be the most effective point of access to the services. It will be important to know who the key worker / care coordinator is and how far it is possible to develop a good working relationship. Ideally this relationship would include your relative, yourself as informal carer and the care coordinator - this is not always easily achieved as the care coordinators professional obligation is to meet the needs of your relative. This means that if your relative prefers not to have you involved, the care coordinator is unlikely to communicate with you about your relative on grounds of confidentiality.

## New & recent services

New types of services are being developed to address different problems and situations; for example

- home treatment should be available as an alternative to hospital admission -this is often suitable for people who might have problems coping in the environment of a hospital ward
- crisis teams might provide support to people in their own homes, offering a fast response, available around the clock
- crisis places may be available as an alternative to hospital in-patient care, in 'crisis homes' which can provide a safe and acceptable environment

- assertive outreach services may offer intensive support to people who are likely to lose contact with the mental health services

## **Actions you can take**

Where a full range of services is not available, you may want to take action to improve the situation. Suggestions include:

- being proactive in identifying those needs which your relative has that are not being met by existing services - you should be assertive in alerting the care coordinator to those unmet needs
- participating in any initiatives your local authority plans for involving people with mental health problems and their informal carers in developing mental health services
- joining forces with voluntary agencies such as Rethink or MIND where they have support workers or development workers, in order to press for implementation and development of services
- acting collectively with other informal carers to lobby your MP and/or Councillors to maintain and improve services
- using the established complaints procedures to seek redress and improve the quality of services

## **Helping with Practical Matters**

**If your relative is experiencing severe depression or the negative symptoms of schizophrenia, they are likely to find daily activities such as cooking, shopping and managing money, difficult to cope with.**

It may seem strange that a person who is recovering from psychosis can talk eloquently about current affairs, but find it difficult to cook a meal for themselves, or fill in a benefits claim form.

But this is often the case.

Informal carers can help first of all by accepting this. Remember that your relative is not being lazy or wilful in not doing these routine tasks. They need support in managing the steps in what will now seem like very complicated tasks.

## **What you can do to help...**

As an informal carer your encouragement to take advantage of any life skills training available during rehabilitation will be very important. You might take responsibility for one or two steps in the process but gradually withdraw as some independence is regained.

Informal carers can help further by completing benefit forms, with the help of Citizens Advice Bureau (CAB) or specialist agencies like Rethink.

## **Points to consider**

Your relative may not always have the mental capacity required to manage their own affairs and so together you will have to decide how much responsibility your relative should have, how much assistance will be required and in what respect.

There are several options to consider in this situation:

- acting as an agent, where your relative allows you or another person to collect benefits for them
- becoming your relative's 'appointee' so that you can claim benefits on their behalf when a mental disorder prevents them from doing so getting a 'third party mandate' at the bank, where your relative authorises you to sign cheques on their behalf
- using a 'power of attorney' which could be 'ordinary' or 'enduring', where your relative empowers you to act on their behalf with regard to some or all financial decisions, perhaps only during episodes of illness
- involving the Court of Protection which is normally only appropriate if there is a substantial amount of money or property. In these cases a 'receiver' will be appointed.

# Encouraging your Relatives Independence

There is growing evidence from research that if a person with severe mental illness regains enough stability to manage their illness alone or by sharing responsibility for care and treatment with their key care coordinator, living independently of their supportive family can be helpful.

For someone who has felt so powerless in the face of frightening symptoms, the decision to live independently can be momentous.

It involves starting to take everyday risks that have previously been found as overwhelming - for this reason any move towards independence needs to be done gradually. Recovery involves mastery of skills a little at a time and the same step-by-step approach may be needed in regaining social independence.

Mental health professionals increasingly encourage people recovering from mental illness to take small steps, in order to help them begin to set short and long-term goals. Achieving goals will gradually help towards rebuilding self esteem, and allow people to effectively manage their anxiety in order to be able to regain some control over their life.

## Knowing when and how to let go

As your relatives recovery progresses, this will continue to need care and support from their family and carer, but it is important to understand and be comfortable with the situation when the time comes when they no longer need you to care for them.

This is probably the time to start trying to step back and let go. The family carer, knowing how dramatically and painfully things can go wrong, will almost certainly continue to worry - they know how vulnerable their relative is and how harsh the world outside can be to those with mental illness. You also know that professional help is not always available or sufficient to meet their relatives needs, and so your urge to protect will still be there, but you can begin to change the ways that it is shown...

- try to spend less time with the recovering person, as this lets them have time and space to get to grips with their new status in their own way
- try not to constantly worry about what your relative is doing or how they are managing - this can lead to too many checking-up calls which may knock your relatives confidence that you think they can manage

- offer to work alongside your relative to achieve goals that they have set - but be accepting when there may be certain things that they would like to do on their own
- help your relative to make decisions if they seek support in this way support their choices wherever safe to do so, even if you personally have doubts
- be available to support them on a regular basis if needed, but at a regular time chosen by both of you, so that it does not encroach upon the other's independent time

If as a carer you respond to every call for help on demand, no independence will be achieved by either of you.

**With thanks to Rethink**