

Handout 2

Background and briefing paper on caring for someone with a mental illness

Caring for someone with a mental health problem or mental illness

It is not certain how many of the 370,000 carers in Wales are carers for someone with a mental health condition. If the same percentage was used that has been used in the survey of carers of households in England, the number of carers of people with a mental health problem in Wales is about 48,000.

Mental illness is often surrounded by prejudice and ignorance, and people identified as having mental health problems regularly face stigma and discrimination. For many it remains a hidden illness, and there may be some families who do not wish their community or even extended family to know about the mental health condition of their loved one. The next section highlights some of the key points and issues that are specific and unique to carers of people who have a mental illness.

Nature and characteristics of living with a serious mental illness

People living with a serious mental illness (such as Schizophrenia, Bipolar disorder or other type of psychotic illness) are extremely vulnerable, usually have highly complex needs and may often lead chaotic lives. It is often the carer or the family who sees the impact this has on the person they are caring for on a daily basis, and who will spot the signs that the person may be becoming unwell and in need of early professional support, care and treatment. The symptoms experienced by a person with a serious mental illness may be episodic, which means for much of the time the person may be well.

Mental illness is the only illness whereby a person experiencing it may be detained, and receive compulsory treatment against their will (Mental Health Act 1983 as amended). This can lead to tensions within families and potential disputes and disagreements between the person with a mental illness and their carer or family.

For some people it is this perceived threat, or risk of detention/sectioning under the Mental Health Act, that leads to them behaving differently when they meet

with a health and/or social care professional. It is often the carer or family who sees the person as they really are.

There is a specific stigma and discrimination associated with mental illness. This is sometimes exacerbated by the involvement of the police and/or other criminal justice agencies, displays of what other people may consider bizarre and/or threatening behaviour, and sometimes there is a link to the overuse or misuse of drugs and/or alcohol.

When someone living with psychotic illness is unwell they may appear delusional, display signs of paranoia and/or experience hallucinations. The carer usually has most insight into what is happening and may at times be the focus of the delusion as the nearest person.

Often it is left solely to the carer/family to support the individual through this trying and very difficult time. There can be tensions, conflicts and feelings of guilt within families. This is a unique and specific aspect relating to people and families living with mental illness.

The need for mental health specialist support

Both people living with a serious mental illness and their carers or families need specialist care, support and treatment due to the nature and complexity of the illness, as well as any potential legal consequences.

Many carers of people living with a serious mental illness are a 'Nearest Relative', and as such have certain rights and powers under the Mental Health Act 1983, e.g. to be consulted, to be able to ask for an assessment, to request that their relative is discharged from hospital, to seek support from an independent advocate, etc.

Often carers of people living with a serious mental illness say they are not given information regarding the care and treatment of their loved one with professionals often citing 'confidentiality' as the reason. (*The Code of Practice to Parts 2 and 3 of the Mental Health (Wales) Measure 2010 does allow professionals to consult with a carer against the patient's wishes where it is considered to be in the patient's best interest*).

The use of advance directives and advance statements¹ may often be appropriate for safeguarding and promoting the wishes, feelings, interests and health of a

¹ Advance directives and advance statements are documents drawn up by individuals when well to express their wishes as to their future care and medical treatment when they may be unable to express those wishes themselves.

loved one. They are likely to have a significant place in the care and treatment of people who fall under the Mental Health Act.

Generally, carers of people living with a serious mental illness would prefer to receive services that directly engage with the person they are caring for, and do not draw such a distinction between the needs of carers and the needs of people being cared for.

It is likely that only support workers who work within mental health will develop the knowledge, expertise and have access to resources to provide effective support when complex and difficult issues arise relating to the carer and the person cared for.

Generic services often emphasise “signposting” to other services rather than providing comprehensive support. Specialist mental health support workers are able to devote more resources and knowledge to help resolve the issues that arise.

It is particularly important to ensure that an assessment of a carer's needs (carer's assessment²) is completed as early as possible to ensure information, advice, support and assistance is easily available to help prevent the deterioration in their loved one's condition and help prevent potential admission to hospital.

Frequently carers do not get in contact until a situation occurs that involves statutory mental health services. This requires an immediate response which is less likely to be available from a generic carer service because of a lack of detailed knowledge of mental health legislation and policies.

Investment in specialist mental health carer services has a long term (and sometimes short term) economic benefit to health and social services. Specialist mental health carer support services are able to provide support to carers, and indirectly to the cared for, which can avoid crisis management. For example, where early signs of relapse are detected, third sector staff with mental health experience/knowledge can support a carer to provide a stronger case to statutory services for early intervention that may avoid a costly in-patient stay.

² A carer's assessment is a way of identifying your needs as a carer. It looks at your role as a carer: how being a carer affects you, how much caring you can realistically do (while still allowing you to be involved in other activities outside caring), and any help you may need.