



Do you
need
a hand
2 care?

What it Means to Make a Difference

A booklet for Carers and families of
people with a Dual Diagnosis in Bolton

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“Caring for a loved one with dual diagnosis is very stressful for the carer and the person you love can be badly affected by your stress. It is important to look after yourself – this is in no way selfish or uncaring, but rather it can help rekindle the flames of love and respect for each other rather than smothering them”

Introduction

Carers are increasingly being recognised for their expertise and knowledge, and their role as essential partners in the treatment and recovery process.

Carers of people with dual diagnosis often say that services simply don't understand the problems they face. "Service users say they want people to listen and to understand what it's like for them when they are in distress – and it's the same for carers. Caring rarely stops when the person being cared for enters services. Carers can be integral to a service user's support system, and their input can substantially improve that person's chances of recovery."¹

This resource 'What it Means to Make a Difference' was first produced as part of the National Dual Diagnosis Programme in 2007 to help identify the needs of carers and to get carers and families of people with a dual diagnosis more directly involved and to provide information and support for them. The programme came to an end in 2010 however the messages are still the same.

Thanks to funding from the Bolton Carer Demonstrator Site Project, this publication has been re produced as a Bolton edition, to help support carers of people with a dual diagnosis living in Bolton and is part of a raft of service developments which will improve service users and their carers journey in and out of mental health and drug and alcohol treatment services and work towards recovery.

Thanks also to Suzanne, Anne and Pat who contributed to the development of this booklet, and special thanks to Christine for allowing us to include one of her poems.

Please note the CD Rom which accompanies this booklet is the copy made for the original national resource, and thanks again to all the carers and families involved in filming the documentary, and of course to Tom Dodd my colleague and friend for interviewing all the passionate men and women who gave their time and shared their stories to make this documentary possible.

Ann Gorry

Bolton Dual Diagnosis Development Lead

¹ *Triangle of Care – A Guide to Best Practice in Acute Mental Health Care – 2010*

1 So, you're a Carer...

Looking after someone with a dual diagnosis can be isolating and stressful. Due to the complexities of this condition the carers own mental and physical health could be affected by the demands from this role².

You will need...

Support; information and a two-way dialogue with services so that you can help the person you care for stay as well as possible and access the appropriate services in order to begin their recovery. This booklet is designed to help you with this communication.

It's not unusual to struggle with the relationship you have with the person you care for. You may have to learn to find a balance between protecting and over-protecting them, which isn't always easy.

Even when local services provide support for your relative, as a carer you may find you are not getting all the help you need. However services are there to help you too.

This booklet is designed to help you get the best from them by providing you with local information and giving you some helpful hints and prompts to assist you when dealing with people working in provider services.

It will also provide local information about organisations and groups available in Bolton which may provide you with help, advice and support, a listening ear, and sometimes a shoulder to cry on when you need it.

2 Caring for Carers; Dept of Health, 1998

2 The Setting

Mental health and concurrent mental health and substance/ alcohol use (dual diagnosis) is not something experienced by one person in isolation, although it often feels like that for carers. This condition can have a powerful effect on a person's relationship's – especially with families and friends.

Services have not always recognised the impact on all the people involved who often may have to make enormous sacrifices to care for someone displaying behaviours and attitudes that even professionals may find difficult to accept and fully understand.

Mental health problems and difficulties arising, especially a severe psychosis, can be frightening for those experiencing it – but carers not only have to deal with some of the most acute disturbances their loved one is suffering, they may also feel isolated, confused and unsupported and not know where to turn for help.

Service users may be the ones that are carrying the burden of their illness, however, their problems impact on a number of people, especially family members, and can turn a stable home life upside down.

When people become mentally unwell, many features of their lives can be affected..... Work, relationships, family and all the other elements which make up a person's life. When drugs and/or alcohol is included in the mix, the whole problem for carers takes on dimensions that few people (except those who have experienced it) can even begin to imagine.

3 What is “Dual Diagnosis”?

Dual diagnosis is not a diagnosis in itself but is a term used to describe people who have both a mental illness and problems arising from drug and/or alcohol use. The condition is surprisingly common.

Studies have shown that:

- Over 1/3 of people with a severe mental illness admitted into hospital will also have concurrent alcohol and/or drug problems
- Over half of people in substance misuse services with higher rates in alcohol treatment teams also have mental health problems
- 70% of prisoners report having substance misuse and some mental health difficulties
- High rates of dual diagnosis within specialist mental health teams such as Assertive Outreach and Early Intervention Teams

There are a number of challenges associated with dual diagnosis that can make the situation for carers very difficult.

ONE

The definition of what constitutes “dual diagnosis” varies from practitioner to practitioner and between services. (In fact, practitioners often talk about ‘complex needs’).

TWO

There’s a huge diversity in the way the two conditions affect each other and there are different ideas about the best way to treat them.

THREE

There can be a number of agencies involved in a person’s care including mental health services, specialist drug and alcohol services, primary care and other organisations in the statutory and voluntary sector. As a result, care risks being fragmented and individuals and their carers may find it difficult to navigate across a number of agencies and services.

FOUR

Historically, substance misuse and mental health services have evolved separately. Few services are currently set up which deal with clients' substance misuse and mental health problems at the same time. Service users have tended either to be treated within one service alone, which has meant that some aspects of their cluster of problems have not been dealt with as well as they might, or have been shuttled between services, with a corresponding loss of continuity of care.

While a proportion of service users needs have not been met because of these barriers, carers needs have often been neglected also.

In Bolton there have been a number of developments over the last few months and we now have a structure in place to begin to build on many of the recommendations from the recent Dual Diagnosis Report which has outlined a number of areas for improvement, in particular around bridging the gap between mental health and drug and alcohol services. This work is underway but will take time before the structures and appropriate training and awareness raising programmes are fully implemented. It is only then that we will be able to see real service improvement for users and carers. But it will come; we just need to keep moving forward a step at a time and work together.

4 Getting Support

Carers report that some of the best help and understanding comes from other carers and local carers' support groups. Few carers' groups actually set themselves up to support dual diagnosis in isolation. In Bolton there are a number of groups which are actively involved in trying to improve services for carers of people with a dual diagnosis and are members of the local operational steering group.

The Harbour Project is a voluntary organisation which provides support to parents, families and carers affected by someone else's drug or alcohol misuse.

The Project offers support, practical advice, and drugs awareness information, regular group meetings where you can share experiences with others, one to one support, and a confidential 7 day telephone helpline tel: 01204 62274 for more information.

Making Space recognises that carers lives are deeply affected too. That's why we created the Making Space Carer support service so that people like you – people who are committed to the care and wellbeing of their loved ones also get support, someone to talk to and a powerful voice to represent you. Also have the backup and opportunities to enjoy a much improved quality of life. For further support and information please contact your local Making Space Support Worker on: 01204 390390 ext. 3497

More information on local services for carers can be found on www.gmw.nhs.uk under service users and carers page

Take this booklet with you if you are meeting professionals or other carers and grab all the contacts and addresses you can. Use this page to note down any numbers of useful local contacts or agencies even if you don't call them at this stage.

STATUTORY SERVICES

General Practitioner or Family Doctor:

Community Psychiatric Nurse (CPN):

Care Co-ordinator

Hospital

Alcohol or Drug Service

Police

Other

VOLUNTARY AND OTHER SERVICES

Other Carers

Carers Groups

Key Worker

5 Crisis? What Crisis?

Carers can be the first to be aware of a developing crisis – often at times when professional help has not yet been established. Carers can often be best placed to notice subtle changes in the person for whom they care, and are usually the first to notice the early warning signs of a relapse.

Section 6 gives some useful advice about what a carer can do in a crisis at home. It addresses the sorts of circumstances which most carers would recognise as the moment when a situation has become, or is in danger of becoming, out of control.

However... New carers learn very quickly that their version of “a crisis” is often very different to the one held by the care team responsible for the service user. It’s important that this doesn’t lead to any friction between the carer and the care team; different agencies have different priorities in the way they approach mental health/substance misuse and the staff are expected to comply with the policies and procedures established by those agencies.

Work is progressing in Bolton to connect all the different services involved to develop a collaborative joined-up approach to care. For some carers it doesn’t always feel that services are working together.

For professionals, (and despite an individual worker's personal response) a crisis will tend to be defined in terms laid down in advance by the agency they work for and will contain a strong consideration of risk and public safety together with the level of human resources they have available.

For many carers, a crisis can be defined as a time when they can't personally cope with a situation any longer and everything is at risk of getting out of their control.

Carers' crises often come when they can't cope any more and need desperately to talk, to cry, even to scream with frustration; they often need to be taken out of the situation or have someone else manage the problems for a while.

These two different perspectives often exist between carers and mental health/drug and alcohol services. Carers need to understand these difference of view so as not to add to the frustrations they may already have!

It is important to ask questions and get support where you can and when you need it.

6 Dealing with a Crisis

Tips for Carers

Do's in a crisis situation³

- **Do** try to remain as calm as possible, and if you can, create a calm environment and try to limit any potential distractions i.e. TV, radio, music etc
- **Do** allow personal space; do not crowd your relative. Under no circumstances attempt to physically restrain them. If you fear they are presenting a risk to others in the house get everyone out of the house, don't attempt to force your relative/friend out of the house. Call for help or the police if necessary
- **Do** contact the person's GP, social worker or key worker if they have one for advice
- **Do** ask other people in the room/ house, especially strangers, to leave. Talk only one at a time, speaking normally and clearly as you usually do
- **Do**, if you can, ask simple questions about the behaviour that you are observing, rather than state your opinion about what you believe to be happening
- **Do** look at your position in the room, what message are you inadvertently giving out by sitting or standing where you are? What's your body language saying? Are you actually looking hostile while feeling scared?
- **Do** try to stay calm. Even though it's difficult, your high expressed emotion like anger and frustration will only make the situation worse.

³ Do's and Don'ts from: *Through the Maze*, Georgina Wakefield, Fivepin Publications, 2006

Don'ts in a crisis situation

- **Don't** shout or speak loudly; if they are not listening to you try to imagine what might be going on in their head, no matter how strange it may seem
- **Don't** criticise, they might not be able to follow a reasoned argument at this point. Don't even try to tell someone what they should or shouldn't do
- **Don't** make continuous eye contact, it can be stressful and confusing
- **Don't** argue. If they say they can hear voices or are hallucinating say that you are not aware of them but avoid saying that they don't exist

- **Don't** get too close or try to frighten or intimidate the person into compliance with your wishes
- **Don't** argue among yourselves about what to do and ensure you don't block any doorways
- **Don't** repeat unnecessary questions or statements.

Carers, especially new carers, can be thrown into a set of circumstances which can be hard to manage or understand. Make contact with other carers and use their experience and knowledge to help in a crisis.

7 Entitlements

You are entitled to:

Respect, sensitivity and professional consideration from all support workers and practitioners involved in the care of your relative.

- A carer's assessment^{4,5} (see more in next section)

You may also be entitled to:

- Financial support from the state or local authority
- Support for the whole family
- Respite breaks so that you can keep well enough to care.

You are entitled to information about:

- Your relative's health problem and treatment – subject to rules of confidentiality
- How to provide care
- How to get care and support for yourself, and
- Local support services, both statutory and voluntary.

Your entitlement to an assessment; to direct payments, benefits and personal support – Information available on the Bolton local authority website: www.bolton.gov.uk

4 National Service Framework for Mental Health; Dept of Health, 1999

5 Carers and Disabled Children's Act 2001

8 Carers' Assessments

If you provide a regular and substantial amount of time looking after a relative or friend with dual diagnosis, then a Carers' Assessment could be very helpful to you. The assessment is completed at your request, and can remain confidential if required.

A Carers' Assessment is not a test of what you do as a carer.

Carers are entitled to a carer's assessment annually, whether or not the service user is engaged with services or not. If you are providing significant care then you will be entitled to a care plan of your own.

A Carers' Assessment is your opportunity to talk about the things that could make life easier for you and to look at what would be helpful in your situation.

An assessment may take into account:

- The help the person you care for needs

- The help you are giving at that moment
- The support that may be provided.

A carer's assessment is an opportunity to look at your needs, your health and wellbeing and whether you wish to receive support.

It will cover areas such as:

- Need for information
- Need for a break or time away from the person you are caring
- A need for practical, emotional or financial support
- Look at opportunities for leisure, employment and a 'life of your own' alongside your caring role
- Contingency planning and managing a crisis
- It will also take into account any cultural, spiritual, gender, lifestyle or other needs you may have.

As a carer you will be entitled to an assessment if:

- You provide ‘regular and substantial’ amounts of care or support, and
- You request an assessment.

The assessment is reviewed on an annual basis to see if your circumstances have changed and if any change to the support offered are necessary

If you are a carer of a person with dual diagnosis you should be automatically offered an assessment, but don’t take anything for granted...

As a carer you should also be able to contribute to the discussion about the needs of the person you care for (their assessment). If you do not wish to have an assessment in your own right, there are still services which are available to you.

Regular and Substantial amounts of care or support is where a carer:

Provides long hours of help (approx. 20 hours per week), and carries out a range of helping activities, and/or is likely to provide both personal and physical assistance.

You can always talk to your assessor to see if:

- Your caring role is substantial
- Your caring role is less than 20 hours per week but intensive, and there is a risk to your caring role not being sustainable.

To request an assessment speak to the Care Co-Coordinator for the person you are caring for.

9 Service User Confidentiality

“Confidentiality is often seen as a problem area in creating a Triangle of Care. The therapeutic relationship between worker and service user is based on having ‘confidence’ or trust that what is said will not be disclosed without their agreement. This agreement needs to be considered in the context that the carer may have key information relevant to safe and effective care planning for the service user. They may also be required to take on roles and responsibilities to achieve the best care plan in the home or once the service user is discharged.

Carers should be encouraged to share this information, not only because it will help the clinical assessment and treatment, but also because it gives them a positive role and confidence in the programme. Consideration needs to be given to the fact that crisis, especially involving the need

for compulsory treatment and/or admission may provoke user/carer conflict that may temporarily prevent consent to sharing information.”

The Triangle of Care

Staff should share general information and appropriate personal information with you to assist you in managing a healthy balance between being kept informed and respecting your relative/friend's privacy. It is often useful for carers to receive written as well as verbal information on subjects such as mental health services, rights of the person if they are detained etc. This might be particularly important if the carer is new to the role as negotiating mental health and drug and alcohol services can be a daunting experience and it might help the carer to have an idea of the care their relative is likely to receive.

Professionals should see carers as potential partners in supporting mental health care pathways. Through effective communication, more collaboration is possible, with everyone understanding the responsibilities and rights, needs and concerns of each other. Many of the conflicts that arise through information sharing can be averted if a collaborative care model is promoted.

More information is available from Rethink's e-learning package: www.carersandconfidentiality.org.uk.

Issues around confidentiality should not be used as a reason for not listening to carers, nor for not discussing fully with service users the need for carers to receive information so that they can continue to support them. Carers should be given sufficient information, in a way they can really understand, to help them provide effective care¹.

Carers give:

Their understanding. Often carers are the ones who know the service user best and have dealt with their welfare over many years.

Their commitment. While services and the people they employ are constantly changing, carers are frequently the only constant service users may have.

Their patience. Both crises and the seemingly endless round of day-to-day problems that arise with service users with more complex needs mean that considerable sacrifices may be made by carers.

Their willingness to share. The well-being of the service user and their carers improves when they are surrounded by a team of professionals working together towards recovery.

So why do they so often feel left out?

The service user has not given their consent to the sharing of information with the carer.

¹ *6 Developing Services for Carers and Families of People with Mental Illness, DoH, November 2002*

Professionals involved in service user care have a duty to follow professional codes of practice, common law and statute regarding confidentiality.

At times of crisis, relationships can be strained and the family may be exhausted and stressed. The professionals may get a false picture of the true long-term situation.

Good practice⁷ for professionals means you can expect to be given:

- The diagnosis (if there is a confirmed one, often this can take time)
- Information on outcomes and behaviour
- Benefits and side effects of medication
- Local in-patient and community services
- The Care Programme Approach (CPA)
- Information about local support groups.

... help to understand:

- The present situation
- Confidentiality restrictions of the service user
- Patient treatment plan and its aims
- The relevant elements of a written care or crisis plan
- The role of each professional involved, and
- How to access help, including out-of-hours.

... to receive:

- Opportunities to see a professional alone
- Rights to your own confidentiality
- Involvement as a valued contributor
- Respect for your views and concerns
- Emotional and practical support
- An assessment of your own needs and a care plan.

7 Adapted from Carers and Confidentiality in Mental Health, Royal College of Psychiatrists, 2004

10 Questions for the Psychiatrist and/or Care Team

Carers need information. Carers may not always find out what they need to know about the person they are caring for. This checklist is designed to help you get all the information you can about the diagnosis and treatment of the person you care for.

You should be able to get some of this information directly from other members of the clinical team involved, such as nurses, the drug and alcohol team (DAT), social worker, psychologist, occupational therapist etc, or from written information that they can provide.

Although you may not want to ask all the questions listed, you may find that they help you in preparing to meet the doctor or psychiatrist and the care team. Not everyone will need all the answers to all these questions at the same time. You may have questions that are not covered here. However this is provided as a framework for deciding what you do need to know⁸.

A psychiatrist will be able to give you information about your service user's condition and care but specific clinical details may be confidential.

8 Adapted from a Checklist for Carers of People with Mental Health Problems, Royal College of Psychiatrists 2004

About the illness

- What is the diagnosis or problem?
- Is a diagnosis necessary?
- Why has this happened?
- Will they recover?

About a diagnosis

- What symptoms suggest this diagnosis?
- What are the causes?
- What is likely to be the course of the illness?
- Where can I find more information?

About the assessment

- What assessments have been carried out?
- Will there be more assessments?
- What are the drug/alcohol problems diagnosed?
- What will need to be done about them?
- Has culture and background been considered?

About care and treatment

- What are the aims of proposed care and treatment?
- What is care co-ordination and “CPA”?
- What does the care co-ordinator do?
- Who else is involved in care and treatment?
- What happens if they refuse treatment?

About information sharing

- How much information will I get?
- Will I be informed of meetings and reviews?
- Can I see you on my own?
- Can I speak confidentially about the service user?

About the carer’s role

- What can I do to help?
- Are there local self-help/other groups?
- Where is there advice and training for carers?

About getting help

- How can I get in touch with you?
- How do I arrange to see you?
- Who do I see if I’m worried about their behaviour?
- Who do I contact in an emergency?

About medication

- What is to be used and how?
- What are the benefits?
- What are the side-effects?
- What symptoms might mean a change of dose?
- What will happen if they stop taking medication?
- What do I do if they stop taking the medication?
- Where can I find more information on it?

My own questions:

11 Carer Consultation/Involvement

In England there is a requirement for carers to be consulted, with or without the service user's consent, before a Supervised Discharge Order⁹ can be implemented.

However, guidance from the Department of Health about protecting service user confidentiality is inconsistent over the question of whether or not carers are members of the service user's 'care team' in the community and so entitled to detailed information about the service user's discharge, even where it can be shown that the informal carers are a key part of the support provided in the community.

Government guidelines to mental health services state that they have a duty to inform and involve carers.

Getting agreement

First step: Get agreement with the person you are supporting and their treatment team about the level of your involvement and access to information about what's happening and what's proposed. This probably needs to be done at a time when the service user is reasonably well and certain protocols can be agreed between principle carers, the treatment team and the service user about who's involved and who isn't.

Carers should also be clear to what extent they themselves are seen as one of the "treatment options" for a particular service user. Treatment teams may assume that a parent who has been looking after a son or daughter for 5 or 10 years will simply go on doing so on discharge.

A care plan is a written document produced by the care team which identifies:

a) the patient

⁹ *Mental Health (Service users in the Community) Act (1995)*

- b) their current situation
- c) who is involved in their care
- d) what roles the care team has
- e) what the objectives are for treatment and on-going support.

Key questions which require answers at the care planning stage are:

- Does the person being cared for actually understand what's on offer and the consequences of declining that kind of support?
- How insightful is the person to the conditions affecting their mental and physical health, and
- How able are they to think their way through the treatment options?

If the service user has difficulty with these questions, the treatment team needs to consider whether the service user has the capacity to make a judgement about the options available and, consequently, the role of informal carers.

Carers may have other questions which they should ensure are answered by the treatment team:

- What, if any, is the possible harm that could come to carers – or the service user – and what is the probability of it occurring?
- What alternative treatment options are there that could reduce the risk of harm?
- What about broader family involvement? There are issues of confidentiality that have to be considered as well as the presence of various tensions and rivalries that may circulate through a family. The treatment team needs to be mindful that once the immediate crisis has passed how likely is it that the service user would see a wider family involvement as having been something that they wanted or not.

12 Useful research

In 2004 the mental health charity Rethink carried out research into dual diagnosis and issued its findings in the report: “Living with Severe Mental Health and Substance Use Problems.”¹⁰ (Rethink, 2004) For the participants, both service users and carers, the types of issues encountered were very typical of what carers generally say about these complex problems:

They were concerned about the diagnosis process. Some carers thought it helpful but others didn't have the same optimism. Some said it may provide access to specialist services, but others saw the potential for increased labelling and stigma. The diagnosis was seen in some cases to increase dependency, reducing a person's motivation to self-manage. For others there were concerns over the perceived unreliability of both assessment and diagnosis.

Service users were almost equally divided on whether mental health problems or substance use were most problematic for themselves. This illustrates the highly individualised nature of these issues. Among carers in the study, substance use was highlighted as the most difficult thing to deal with in the family.

Both groups noted that substances had sometimes appeared to enhance well-being in the short-term while adding to long term difficulties of withdrawal. However they felt long term substance use was particularly problematic and impacted on finance, health and well being.

10 www.rethink.org/about_mental_illness/dual_diagnosis/useful_contacts.html

Common themes identified by both service users and carers talking about their relatives was the sense of shame and guilt, loss of motivation or purpose in life, low self-esteem, and low self-confidence. The most frequently cited impacts on carers were: stress, powerlessness, anxiety and pessimism for the future.

For service users the social impacts were most clearly seen in relationships with family and others, inability to obtain employment and their involvement with crime to fund drug and alcohol addictions. Carers, speaking for service users however, identified the social impacts as social isolation, stigma and lack of employment.

Carers, speaking for their own experiences saw the impact on the whole family, and particularly family relationships, as most noted alongside their fear of physical and verbal abuse and loss of personal freedom as a result of their carer role. Both service users and carers talked about the financial pressures as a result of living with a dual diagnosis both in terms of finding money for the addiction and in some cases families paying for private treatment in an attempt to get adequate help. This was considered to add additional stresses to an already stressful situation.

13 The way forward

The latest Department of Health Carers Strategy states that: *'Carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to be a full and equal citizen.'* (Recognised, valued and supported: next steps for the Carers Strategy (Nov 2010) www.dh.gov.uk/en/SocialCare/Carers).

Carers need hope that the loved one they care for can recover from this complex and often challenging condition, although it may take some time before they reach that point. However, if support is available and you as a carer are better equipped to know the best path to go down to get the right help for you and the person you care for.

We hope this booklet has provided you with some useful information and helpful guidance. Remember talk to the care team: Get support from other carers when and where you can: Use this booklet as a guide and a prompt whenever you need it and use the information provided to help navigate to find the best pathway for you and the person you care for.

"Recovery means being empowered to search for a better quality of life. It means fulfilling potential, personal growth, and having a purpose in life, through inclusion alongside others in communities. It means finding friendship, happiness and wellbeing. Above all, Recovery gives back hope."

Taken from the Stockport Recovery Network website

www.stockportrecoverynetwork.org.uk

Additional Information

There are several types of mental health problems and they can be categorised in a number of ways. There is no complete agreement either about the categories of mental illness or about the symptoms of each but the following are generally accepted as reliable.

- A: Anxiety
- B: Bi-polar disorder (which used to be called manic depression)
- C: Alzheimer's Disease (Dementia)
- D: Depression
- E: Eating disorders
- F: Obsessive compulsive disorder
- G: Personality disorder
- H: Schizophrenia

A: Anxiety

Anxiety disorders are thought to be rooted in different types of stress. The stress which causes someone's anxiety may not be in the present or even known to the individual or their carers. Often people are completely bewildered

by why they are suffering such unpleasant symptoms. Indeed, looking for answers in places where the symptoms appear most vividly, either at home or at work, may not reveal much of the root causes. The symptoms include loss of concentration, persistent fear of the worst possible outcomes, disturbed sleep, impatience and intolerance etc. Other conditions such as phobias and panic disorders are usually included under this heading.

B: Bipolar Disorder

This disorder is characterised by radical mood swings. These are not the same as the common changes of mood that many people experience. The moods can swing from deep despair to intense elation or from a "normal" state to one of these extremes. How the two stages are linked in time is different in all cases, some people may switch from one type of state to another quite rapidly giving the impression that they are alternating between the two; others may remain depressed for long periods with only rare episodes of being normal or "high".

C: Alzheimer's Disease (Dementia)

Alzheimer's (which is just one form of dementia) is often not considered along with mental illness but for carers particularly, the effects on family life and normal relationships can be much the same. The principle symptom of Alzheimer's is memory loss which leads to confusion about time and place. Individuals may also neglect themselves or put themselves at risk. Alzheimer's usually affects people in later life, particularly those over 80, but it can happen earlier. Where reasoning becomes muddled, or actions become unpredictable and incomprehensible, carers face many of the same pressures of those who are caring for people with other mental health problems.

D: Depression

Depression is usually a complex group of symptoms which together can, if not responded to, contribute to long-term emotional and psychological disability. Some level of depression is usually found in all forms of mental illness particularly in anxiety states, bi-polar disorder, schizophrenia and obsessive compulsive disorder. For carers this condition can be very wearing

because the cared-for person can seem relentlessly negative and demotivated. Depression can be addressed through various therapies other than medication and of all the conditions, depression is the one which is most likely to be improved through talking treatments.

E: Eating Disorders

Eating disorders – which mostly affect females – are often very difficult situations for informal carers to manage because the individual is often concealing the problem from those they're close to. Additionally, at the route of severe eating disorders may be in the types of relationships which they already have with family members. Bulimia is characterised by frantic bingeing and drastic purging and is the most common form of eating disorder. People with anorexia typically have a very low body weight which can produce serious medical conditions over time.

Carers often feel that the conditions are about attitudes to food or eating and may try to encourage individuals into dietary changes but these responses are likely to fail because the causes are much more to do with feelings of not being in control which in

turn often have roots in poor adaptation in childhood.

F: Obsessive Compulsive Disorder

OCD, as it is commonly called, is actually two related conditions. Obsessions are intense bursts of ideas, words, images, uncertainties, doubts and so on while compulsions tend to be the actions arising from these obsessions as individuals try to mediate the intense distress they cause. People may adopt certain rituals to enable them to deal with the obsessions and the appearance of these is often when carers become aware that there is a serious problem. For the individual, failure to complete the compulsive action/s can result in severe anxiety or even a panic attack. Non-professional carers need to be aware of the complex background to these conditions before adopting a strategy to help.

G: Personality Disorders

Personality disorders are common and often disabling conditions. Many people with personality disorder are able to negotiate the

tasks of daily living without too much distress or difficulty, but there are others who, because of the severity of their condition, suffer a great deal of distress, and can place a heavy burden on family, friends and those who provide care for them.¹¹

Personality disordered individuals are more likely to suffer from alcohol and drug problems and are also more likely to experience adverse life events, such as relationship difficulties, housing problems and long-term unemployment. People with personality disorders are more vulnerable to other psychiatric conditions, and in particular, they are more likely to suffer from depression. More information is available at www.personalitydisorder.org.uk/

H: Schizophrenia

Schizophrenia is a mental disorder that affects around 1 in every 100 people.

The main symptoms are hallucinations (hearing voices), delusions (a firm belief in something that isn't true) and changes in outlook and personality.

¹¹ *No longer a diagnosis of exclusion. Policy implementation guidance for the development of services for people with personality disorder, National Institute for Mental Health in England (NIMHE) (2003)*

Support from families and friends, psychological treatment and services such as supported housing, day care and employment schemes are vitally important.

People who have schizophrenia are rarely dangerous. Any violent behaviour is usually sparked off by street drugs or alcohol, which is similar to people who don't suffer from schizophrenia. If you have an internet connection, try these sites for more information about the types of mental illness and the symptoms.

www.bbc.co.uk/health/conditions/mental_health

www.mind.org.uk/Information/Factsheets

www.sane.org.uk/public_html/About_Mental_Illness/Mental_Illness.shtm

Drug and Alcohol Information

There are many different types of drugs, including alcohol that people use, abuse and can become dependant on. The majority of people who experience mental health problems use either alcohol and/or cannabis, but often these drugs will be used in combination with other substances such as stimulants. You can find information about their effects, both positive and negative, the risks of using them, and help with stopping, cutting down or minimising the risks that come with using them by logging on to www.boltondrinkanddrugs.org

Local services in Bolton

There are a number of agencies in Bolton who provide treatment for people who have a drug or alcohol-related problem:

Bolton Drug Service (BDS) provides counselling and medical treatment for drug use, and the **Community Alcohol Team (CAT)** for alcohol use.

12 Help is at Hand, Royal College of Psychiatrists, from www.rcpsych.ac.uk/mentalhealthinformation/mentalhealthproblems/schizophrenia/schizophrenia.aspx

Addiction Dependency Solutions (ADS) are the first port of call for alcohol users, they provide counselling and will refer people on to the CAT if this is necessary. The Moving On Service, also run by ADS, provides counselling-based treatment, plus support around education, training and employment for drug users.

Some people decide they want to stop using drugs altogether. There are options for people who want to find out more about stopping completely in the community abstinence service, which is run jointly by ADS and Bolton Drug Service. Safe injecting equipment and advice are available from the needle exchange at BDS.

It is important to remember that 'Treatment' is not just about medication. It can focus on many different aspects of your life, like accommodation, work, and relationships.

Treatment choices can include one, or more likely a combination, of:

- Information and advice
- Counselling

- Needle exchange
- Medical – basic health care, and prescribing of substitutes (e.g. methadone) for some people
- Detoxification in the community and support to help you stay abstinence
- Detoxification in a residential unit if this is right for you
- Residential rehabilitation, again, if this is the best thing for you

All services are confidential, unless the worker believes that you or somebody else, particularly a child or children, is in danger, or if there is a police investigation into certain types of crime.

All Bolton's drug services are aware that different people have different wants and needs, and the drug worker or alcohol worker who works with you will make sure your treatment is focused on your goals and make your treatment journey personal to you.

Resources

Local

Bolton Community Alcohol Team (CAT)

Giles House, 43 Chorley New Road, Bolton BL1 4QR
Tel: (01204) 380948

ADS (Addiction Dependency Solutions) – Alcohol Treatment and The Moving On Service

20 Wood Street, Bolton BL1 1DY
Tel: (01204) 393660

ADS is open Monday to Friday:
9:15am to 5:00pm

ADS is a voluntary sector (charitable) organisation that works with drug and/or alcohol users.

Bolton Drug Service (BDS)

Tel: (01204) 544640
Web: www.boltondrinkanddrugs.org

Abstinence Service for Drug Users

Bentley House, Weston Street, Bolton BL3 2RX

Tel: (01204) 544640

The Community Abstinence Service is available Monday to Friday 9:00am to 4:50pm and Thursday 9:00am to 6:30pm

Arch Initiatives

Trident House, 77 Manchester Road, Bolton BL2 1ES
Tel: (01204) 388962

Alcoholics Anonymous

Tel: 0845 769 7555

Narcotics Anonymous

Tel: 0300 999 1212

SMART Recovery UK

Tel: 0845 603 9830
or (01463) 729548

National

Addaction

Web: www.addaction.org.uk

Helps individuals and communities to manage the effects of drug and alcohol misuse and has over fifty projects in England within communities and prisons.

Adult Children of Alcoholics

A fellowship of men and women who have been raised in an alcohol environment and who need support.

Al-Anon Family Groups

Web: www.al-anonuk.org.uk

For families and friends of alcoholics. Al-anon Family Groups provide understanding, strength and hope to anyone whose life is, or has been, affected by someone else's drinking.

Alcoholics Anonymous

Web: www.alcoholics-anonymous.org.uk

Fellowship of men and women who share their experience, strength and hope with each other that they may solve their common problem and help others to recover from alcoholism.

Alcohol Concern

Web: www.alcoholconcern.org.uk

The national agency on alcohol misuse. The Mental Health and Alcohol Misuse Project provides fact sheets, a newsletter and web pages to share good practice among clinicians and professionals.

Carers UK

20-25 Glasshouse Yard, London EC1A 4JS

Tel: 020 7490 8818;

Carersline: 0345 573 369

The national voice of carers. They provide advice for carers across the UK.

Drinkline

Freephone: 0500 801 802

Tel: 020 7332 0202 (Open 11am-11pm Monday-Friday, dial and listen service 24 hours a day)

National Alcohol Helpline. Provides information and self-help materials, to callers worried about their own drinking and support to their family and friends.

DrugScope

Web: www.drugscope.org.uk

DrugScope provides information and publications on a wide range of drug related topics.

FRANK (formerly the National Drugs Helpline)

Freephone: 0800 77 66 00

Confidential, daily 24 hour service:

Web: www.talktofrank.com

Campaign from the Department of Health and the Home Office, supported by the DfES.

Information and advice on drugs to anyone concerned about drugs and solvent/volatile substance misuse, including drug misusers, their families, friends and carers.

MIND (National Association for Mental Health)

Help Line: Mind info-line:

020 8522 1728/0845 766 0163

Local support groups of various sorts. Comprehensive website with advice, information and background briefings on a wide range of mental health issues and mental health problems including dual diagnosis.

Rethink severe mental illness

Web: www.rethink.org

Carers' website:

www.rethinkcarers.org

Runs over 400 mental health services, network of more than 120 support groups across the country.

Rethink National Advice Service

Provides information and advice on all aspects of mental illness and issues affecting people with mental illness to people with mental illness, their carers, friends and family and professionals.

SANE

SANELINE: 0845 767 8000

Concerned with improving the lives of everyone affected by mental illness.

Turning Point

Web: www.turning-point.co.uk

Social care charity providing services for people with complex needs across a range of health and disability issues primarily substance misuse, mental health and learning disability.

Scenes	Approx Length of Chapter	
	Minutes	Seconds
Family Members' Perspectives 1	4	26
Family Members' Perspectives 2	8	32
A Father's Perspective	5	57
Benefits Of Involving Carers	5	35
Caring Changes Lives	4	00
Carers' Contact With Services	3	13
Behavioural Family Therapy	4	02
What Carers Find Helpful	6	45
Credits	2	00

Just Because

Just because I have a label, doesn't mean I cannot feel.
You say I live in a fantasy, but to me it's very real.
When I speak, my words may come out wrong – but you don't listen anyway.
Who cares enough to listen, and HEAR what I have to say?

Just because I have a label, it doesn't make it true.
If fate had dealt us a different hand, all this would be happening to you.
Am I just an inconvenient statistic, for you to dismiss as you roll your eyes?
Be careful how you judge me, condemn me, or despise.

For I was once like you my friend, and maybe I will again.
So tread gently on my dignity, and I'll pray you never share my pain.

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