



## STRATEGIES

# for living

A summary report of user-led research into people's strategies for living with mental distress





## INTRODUCTION

**This report (based on Chapter 5 of the main research report) is based on our belief that, as people with experience of mental health problems (or mental distress), we have our own expertise; an expertise frequently overlooked by those involved in the planning and provision of mental health services. We also believe that we are more than the services and the treatments that we use or receive – that we have a myriad of different strategies or ways of managing or dealing with our distress. The research reported here aimed to explore the expertise of mental health service users in depth and in detail, and to reach a better understanding of what it is like to live with and manage mental distress.**

*Knowing our own Minds*<sup>1</sup> – a user-led survey of alternative and complementary treatments and therapies in mental health – was published by the Mental Health Foundation in February 1997. Over 400 people who had used mental health services returned questionnaires asking them to comment on a wide range of mental health treatments and therapies, as well as a range of other personal and self-help strategies. The research reported here followed up this survey by interviewing 71 people with experience of mental health problems in depth.

This summary gives an overview of the strategies, therapies, supports and activities identified as the most helpful or most important by the people we interviewed. Rather than attempt a summary of the whole report, we have chosen to explore here those elements that people valued most highly in their lives and the reasons they valued them in this way. In one of the early discussions with the interviewees, it was suggested that a key finding of the study might be that ‘everyone is different’. It is certainly true that the complexity of things that people find helpful in their lives, and the reasons they do so, suggests infinite variety rather than any easy categorisation. However, some strong themes emerge across these differences that enable us to learn some general principles about living and coping with mental distress.

## 'MOST HELPFUL' STRATEGIES AND SUPPORT

The following gives an overall picture of the different strategies and supports people had found to be the 'most helpful' to them overall. Many people gave a combination of two or three supports, people, or activities, whilst a few found that one factor alone – or one person – stood out for them.

'Most helpful' strategies and supports	
<p><i>Relationships with others</i></p> <ul style="list-style-type: none"> <li>• Friends</li> <li>• Other service users/people with similar problems</li> <li>• Mental health professionals</li> <li>• Counsellors/therapists</li> <li>• People encountered in day centres, drop-ins, voluntary sector projects</li> </ul>	<i>Medication</i>
	<i>Physical exercise</i>
	<i>Religious and spiritual beliefs</i>
	<i>Money</i>
<p><i>Personal strategies</i></p> <ul style="list-style-type: none"> <li>• Peace of mind</li> <li>• Thinking positively, taking control</li> </ul>	<p><i>Other activities</i></p> <ul style="list-style-type: none"> <li>• Hobbies and interests</li> <li>• Information</li> <li>• Home</li> <li>• Creative expression</li> </ul>

People talked about what they found 'most helpful' in slightly different ways, depending on where they were in relation to their illness or distress at the time of the interview. A number of people described the way in which the value placed on any form of support might vary over time. Different things could be helpful at different times, depending on the nature of change within the illness or distress, and also on the experience gained by the person.

The following broad categories help to describe these different roles, but also demonstrate the immense variation within those roles that could take place between individuals.

**On-going survival strategies** might include the value and significance of financial security, a sense of belonging and acceptance found in the company of like-minded people, work or daytime activities, physical exercise or the support of a religious faith. Taking control through personal and self-help strategies is another survival strategy, as is enjoyment found in a variety of different interests and activities.

**Crisis or life-saving strategies** might include contact with friends or professionals, medication and mental health services, the presence of children as a reason for living, the ethos of a religious faith, or an activity such as artistic expression or sport that can capture the attention away from self-destructive or negative thinking.

**Symptom management** might be achieved through the appropriate use of medication, through alternative strategies to control voice hearing, such as sport and physical exercise or listening to the radio or Walkman, and through strategies developed through talking therapies.

**Healing strategies** might be found through healing and complementary therapies, religious and spiritual beliefs, and through the development of personal strategies to achieve peace of mind.

The overwhelmingly predominant theme running through people's 'most helpful' supports was the role and value of relationships with other people, in all of their different forms. For some people, it was individuals, family or friends, whilst for others it meant the company of people encountered through local day centres or self-help groups. For still others, the important people in their lives were mental health professionals: counsellors or CPNs, support workers or social workers.

One important issue that deserves attention is the relative absence of mental health services and treatments from this list. Mental health services and treatments played an important role in the lives of many people. Medication, when prescribed appropriately, could relieve symptoms and improve mood, and there were a number of mental health professionals who received special mention for the support and the services they provided. In this study, however, the 'most important' sources of help remained predominantly outside of the statutory mental health services. However, voluntary sector projects, some of them local Mind associations, some of them mental health projects serving African-Caribbean or Asian people, and some of them addressing particular life experiences such as sexual abuse, received enormous and grateful praise.

In order to understand the 'most helpful' issue in more depth, it is important for us to explore the reasons why these particular supports, people or activities were nominated as the most important, and to look for any common themes that occur across the different factors. The rest of this summary is based on these common themes.

## COMMON THEMES

- Acceptance
- Shared experience... shared identity
- Emotional support... 'being there'
- A reason for living
- Finding meaning... and purpose
- Peace of mind... and relaxation
- Taking control... having choices
- Security... and safety
- Pleasure

### ACCEPTANCE

It is clear from listening to the people we interviewed that the stigma and discrimination experienced in relation to mental illness made the acceptance of others a vital element of their survival, and frequently a means of achieving self-acceptance. Many people found coming to terms with distress and diagnosis a long and difficult process. In this study we have seen how the value and support, the affirmation and acceptance of others served for many as a valuable and vital route through that process, a lifeline to survival. The issue of stigma and discrimination has been highlighted elsewhere,<sup>2</sup> and most recently in the Mind inquiry report *Creating Accepting Communities*.<sup>3</sup> The interviews reported here suggest that many people experiencing mental distress seek out and create their own 'accepting communities', whether among friends or family, or among other people with similar experiences or a shared identity. Where they cannot do so, or are prevented from doing so, we can only reflect and affirm the isolation and social exclusion that result:

'[Drop-in] is like a safe haven really, from out there... they are just accepted for the person that they are, underneath the illness. That really is the key to it all here.'

### SHARED EXPERIENCE... SHARED IDENTITY

Acceptance was very often found in the company of others who shared similar experiences, or who shared a key aspect of an individual's identity. Some people had discovered the value of shared experience through self-help groups addressing a particular aspect of mental distress, such as sexual abuse or depression, whilst others had discovered it through voluntary sector projects, drop-ins or day centres, where they had met 'like-minded' people. As much as the frequency with which this theme recurred, it was the strength and passion with which it was expressed that

caused it to stand out for us. For some people, finding others who had experienced something similar to themselves was in itself important, because they had previously felt alone with their experiences, and now were able to find reassurance and affirmation of their experiences in the company of others.

There were additional issues of racial, cultural or sexual identity for some of the interviewees, which it was important for them to be sharing with the people from whom they sought help. This support was most frequently found through culturally specific voluntary sector projects, such as Asian or African-Caribbean day centres or projects. It is significant that many of the Asian and African-Caribbean people we interviewed had experienced very little, if any, help outside of these projects; as one Asian woman put it:

‘Only [this project] has helped me. No-one else has ever helped me.’

### **EMOTIONAL SUPPORT... ‘BEING THERE’**

It was mainly named individuals who were identified as providing that most underestimated of functions: just ‘being there’. This included mental health professionals who were available and accessible, people who listened and believed, and close members of the family or friends who had stayed with the person throughout a period or periods of distress. ‘Being there’ was more than just a physical presence, of course; it also meant a sense of safety or security for the person in distress, and a sense of being accepted ‘warts and all’:

‘It’s just that he’s always, he’s been there, and I know he’s there for me, and it’s just knowing he’s there can help sometimes. I do know there is somebody at the end of that telephone.’

### **A REASON FOR LIVING**

A few interviewees identified individual people in their lives, usually family and often children, as an important source of motivation to carry on with the struggle: perhaps because they felt needed as a carer or felt that they needed to be strong for the other person. This often arose in relation to children, but also in relation to a friend or relative who relied on the person being interviewed for care or support. One or two people identified their children as a reason for living, because of the hope they provided for the future or because they could lift them out of depression.

There were a number of other strategies and supports given as a reason for living. Religious and spiritual beliefs were often given as a fundamental belief system that provided meaning in people’s lives and a reason to carry on through deep, and potentially suicidal, distress. One woman described her creative artistic activities as a vital lifeline, that had ‘actually kept me alive’ on more than one occasion.

### **FINDING MEANING... AND PURPOSE**

A few people gave their religious faith as one of the most helpful factors in their lives. As one person expressed it, religion could represent a complex mix of support elements; it could be faith and spirituality, as well as the support of like-minded people. But one of the key underlying themes to having a religious faith was that it sustained people through giving meaning or purpose to their lives.

People could also find meaning in their lives through the care or support of others; often having been supported through their own illness or distress, they felt the need to provide help and support to others in return, to pass on their experience and knowledge, and this gave them a sense of purpose and value. Other people found purpose in their lives through employment or through other meaningful daytime activities, having something to get up for on a day to day basis being a sustaining element of a ‘sense of purpose’.



## PEACE OF MIND... RELAXATION

Several people spoke of the value of achieving peace of mind, whether simply through long experience or through other routes, such as religious or spiritual beliefs, or creative expression. These people had sought out an island of peace or quiet, or patience, within themselves that enabled them to live with their difficulties or to prevent further pressure or stress from affecting them within. For example, one man described his search for peace as a strategy for reducing stress, and related it to his religious belief.

Relaxation was achieved through physical or creative activities, music or complementary therapies (such as massage and aromatherapy) or through finding peace at home alone. Relaxation emerged as a strong theme in the *Knowing our own Minds* survey, where a range of alternative and complementary therapies were explored.

## TAKING CONTROL... HAVING CHOICES

People found different ways of taking control of their distress or taking control of their lives. For some people, it had been vital to develop a positive attitude through self-help strategies. Their personal strategy for self-help had a proactive connotation, involving the encouragement or development of a mental or emotional state within themselves, a positive frame of mind or self-assertion to overcome negative thoughts or feelings. Some people had achieved greater control over their lives through taking a more proactive approach towards the treatments or therapies they used for their distress: for example, learning to self-medicate or using complementary therapies or alternative strategies within a self-help approach. Physical exercise had proved important to a number of people, through enabling them to take control over their physical and mental health and well-being.

An important aspect of taking control is being able to make choices. Some people talked about the importance of having access to appropriate information (for example, finding out information about their medication or diagnoses, or about alternatives to medication), and some talked of the importance of money in providing them with access to more choices in the strategies or activities they could adopt:

‘Because [money] allows me to access everything else, without the money I would be... alone... would have to find a job, I can even stay in the flat I’m living in. So, I would say the money is the most important thing.’

## SECURITY... AND SAFETY

Security could be emotional, physical and/or financial. For some people, finding a secure home had played an essential role in the development of their survival. Financial security was given as the most helpful factor in a couple of people’s lives, because it enabled them to feel secure about their home and standard of living (and because it gave them access to other things – see above). The people who valued their home or money as a foundation for their strategy for living with distress, had either experienced homelessness or financial difficulty, learning by experience how essential are these basic factors:

‘Because you know they’re there, you often don’t actually need to make that phone call, because you think... ‘I feel safe.’

Security could also be about feeling safe in the company of others, an emotional safety that enables trust to develop and distress to ease. Safety in this sense was most strongly highlighted by people who valued and sought the shared experience or shared identity of others; for example, lesbians and gay men, women who had been sexually abused, or people of African-Caribbean or Asian origin.

## PLEASURE

Finally, we turn to the element of pleasure in people's lives. The concept of living with mental distress is inevitably presented as difficult and serious, as earnest and bleak. And of course, this is very often the case; as we have seen above, the stigma and discrimination associated with mental illness brings with it an extra layer of distress that makes life more difficult than ever to deal with. But, we should not also underestimate the fact that people can and do find pleasure in many things, and sometimes in the distress itself. We met a couple of people who had become proud of their distress and their survival. There were also many people who described the pleasure they found in a range of different activities and interests, from creative and physical activities, through to gardening, reading and betting on the horses:

‘Well it’s, maybe, first on the list that helps me, having a bet on the horses, just watch them on television and that. I don’t need to have a bet to enjoy them, like, you know. Watch them on the television and that, I enjoy that a terrible lot.’

## RECOMMENDATIONS

**We recommend that**

- **all mental health professionals, providers and policy makers recognise the expertise brought to the mental health field by the experience of mental health service users**
- **Government establish an Expert Patients Task Force in mental health, in order to build on that expertise to look at the role of people as experts in managing their distress; and to provide advice to the Chief Medical Officer on actions required to mainstream a programme of self-management of mental health problems**
- **Government reviews or replaces the Disability Discrimination Act (1995) with comprehensive anti-discrimination legislation based on a definition of disability that includes people with mental health problems**
- **Government and health education and health promotion agencies support the promotion of positive images of people living with mental health problems both locally and nationally, through a comprehensive anti-discrimination campaign**
- **all mental health professionals take a more holistic approach to mental health and appreciate that individual treatments and services may be only a small part of the whole strategy adopted by someone living with mental distress**
- **mental health providers and professionals recognise that everyone in distress is an individual and has different needs, preferences and potential ways of coping; and support their ways of coping through their inclusion in relevant care plans and reviews**
- **mental health organisations disseminate information about the range of strategies that people find helpful, in order to assist people to find and develop their own strategies, and to locate alternative sources of help**
- **commissioners and purchasers of services, including Primary Care Groups, encourage and promote the development of local self-help initiatives**
- **all mental health professionals provide information about local self-help groups, voluntary sector services, and user groups to service users**
- **mental health providers and professionals provide practical and administrative support to encourage the development of local self-help initiatives**
- **commissioners and purchasers of services encourage, fund and support the development of local black and minority ethnic voluntary sector projects in mental health**
- **Care Programme Approach mechanisms include the systematic collection and dissemination of people’s personal coping strategies as part of the CPA process.**

1 Faulkner, A (1997) *Knowing our own minds* The Mental Health Foundation, London  
2 Rose, D (1996) *Living in the Community* Sainsbury Centre for Mental Health, London  
3 Mind (1999) *Creating Accepting Communities* Mind Publications, London

## SOME PLACES TO LOOK FOR HELP...

### **African-Caribbean Mental Health Association**

49 Effra Road  
Suite 37  
London SW2 1BZ  
Tel: 020 7737 3603  
email: acmha1@aol.com

### **The British Association for Counselling and Psychotherapy**

1 Regent Place  
Rugby  
Warwickshire CV21 2PJ  
Tel: 0870 443 5252 Fax: 0870 443 5160  
email: bac@bac.co.uk www.counselling.co.uk

### **Depression Alliance**

35 Westminster Bridge Road  
London SE1 7JB Tel: 020 7633 0557  
Helpline: 020 7633 9929 Fax: 020 7633 0559  
email: hq@depressionalliance.org  
www.depressionalliance.org

### **Hearing Voices Network**

91 Oldham Street  
Manchester M4 1LW  
0161 834 5768  
email: hearingvoices@care4free.net  
www.hearing-voices.org.uk

### **Manic Depression Fellowship**

Castleworks  
21 St Georges Road  
London SE1 6ES  
Tel: 020 7793 2600 Fax: 020 7793 2639  
email: mdf@mdf.org.uk www.mdf.org.uk

### **MIND (National Association for Mental Health)**

Granta House  
15-19 The Broadway  
London E15 4BQ  
Tel: 020 8519 2122  
Information line: 0845 766 0163  
www.mind.org.uk

### **Mind Cymru**

3rd Floor  
Quebec House  
Castlebridge  
Castlebridge Road East  
Cardiff CF11 9AB  
Tel: 029 20395123 Fax: 029 20221189

### **National Schizophrenia Fellowship**

28 Castle Street  
Kingston upon Thames  
Surrey KT1 1SS  
Advice line: 020 8974 6814  
Mon, Wed & Fri 10am - 3pm / Tue & Thurs 10am - 1pm  
Tel: 020 8547 3937 Fax: 020 8547 3862  
email: info@nsf.org.uk www.nsf.org.uk

### **The Samaritans**

10 The Grove  
Slough SL1 1QP  
Helpline: 08457 909090  
Tel: 01753 216500 Fax: 01753 775787  
email: jo@samaritans.org www.samaritans.org

### **Scottish Association for Mental Health**

Cumbrae House  
15 Carlton Court  
Glasgow G5 9JP  
Tel: 0141 568 7000 Fax: 0141 5687001  
email: enquire@samh.org.uk www.samh.org.uk

### **UK Advocacy Network**

14-18 West Bar Green  
Sheffield S1 2DA  
0114 272 8171  
email: office@u-kan.co.uk www.comcom.org.ukan

### **UKPPG (UK Psychiatric Pharmacy Group Medical Helpline)**

South London and Maudsley NHS Trust  
Denmark Hill  
London SE5 8AZ  
Tel: 020 7919 2999 www.ukppg.co.uk

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