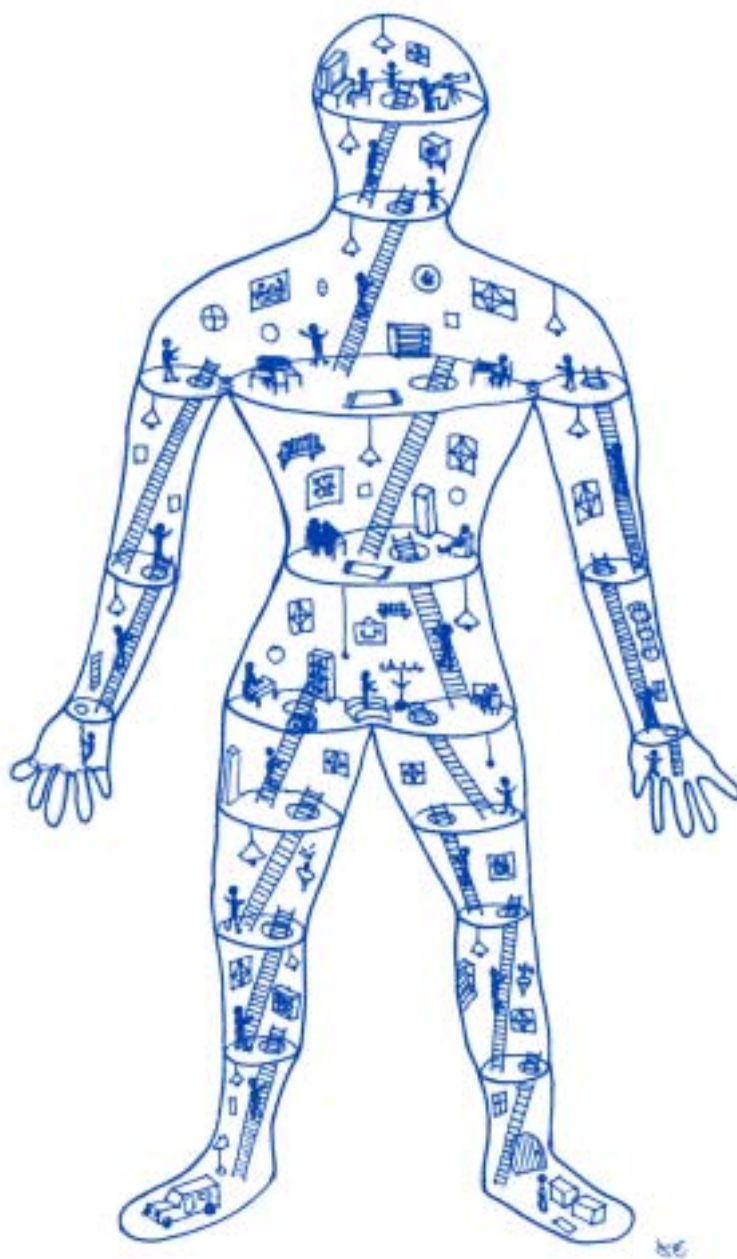


Self-management



The experiences and views of self-management of people with a diagnosis of schizophrenia

Acknowledgements

First thanks go to the fifty-two men and women who took part in the research. They shared their experience and ideas with me in order to help other people with schizophrenia have a better life. They put a lot of thought into their contributions, and a lot of time. Some preferred to remain anonymous, but I am delighted that some agreed to be acknowledged by name. They are:

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The self management symbol (see front cover illustration) was designed by **John Exell**.

The research was carried out and this report written by **David Martyn**.

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A few of the people who took part in the research.

Foreword

It is often asserted that people with schizophrenia are 'experts' by virtue of their lived experience with this major mental health problem. This report amply supports this perspective.

Many of the advances in psychosocial interventions in psychosis owe their development to service users themselves as it is their reports of how they have managed their illness which originally inspired these developments. Thus people with schizophrenia have long described how, with time, they can learn to recognise when they may be becoming unwell ('early signs') and how to deal with it; they have also told us that it is possible to think through and reason with complex, distressing and delusional ideas; similarly many service users have inspired us with their own narrative of how they have recovered and survived the trauma of the diagnosis and its consequences.

This report is rich with detail of service users' own approach to managing their illness which fellow service users and professionals can learn and benefit from.

David Martyn and the service users who have contributed to this report, deserve our congratulations and thanks for putting together such an important and timely report which I have no doubt will be widely read and digested.

Professor Max Birchwood

Introduction

Rethink has for some time been seeking to incorporate a recovery approach into its thinking and provision of services.

The recovery approach recognises the fact that schizophrenia is not, for most people, the progressive degenerative disease that it has been thought to be. On the contrary, many people who receive a diagnosis of schizophrenia are able to manage their condition and recover a satisfying life.

Research on behalf of Rethink found that self-management was a key element in many people's recovery journeys while Voices Forum, the user and survivor network within Rethink, has been promoting self-management for some years.

Rethink, therefore, decided to embark on a further round of research to find out more about how people with a schizophrenia diagnosis used self-management, and what part it played in their lives.

Fifty-two people participated in the research, sharing their experience in interviews and discussion groups, or in writing.

Twenty of these attended a conference to discuss the findings of the research.

This report attempts to present the collective voice of those fifty-two people. The researcher has had to select, interpret and organise their very rich experience, but as far as possible it is *their* voice which speaks through this report.

The report shows that schizophrenia is a condition with serious effects on people's lives, but a condition which can be lived with and managed, given a positive attitude, positive actions and support from others. It also shows that the condition has enriched participants' lives in some ways.

Rethink is building on the findings outlined in this report by developing a programme to support and encourage people with a schizophrenia diagnosis to find ways to be more in control of their lives.

David Martyn
Self Management Project Manager

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1. What is self-management?

“Self-management is what there is if there isn’t one of the other things that can happen:

non-management, where it all goes to pot,

or

management by someone else, where they don’t necessarily make such good decisions as you.

And what’s more, it’s much better if you run your own life because then you have some self esteem to stack up!”
(Zyra)

Self-management means different things to different people. For a few of the participants in the research self-management was:

“Specifically about avoiding or minimising mental health crises. Recognising and acting on danger signals.”
(Bob Axford)

For most of the participants, however, self-management was understood more broadly.

One participant expressed this view as:

“Self-management entails both a positive mental attitude ... and positive actions that help you get on with living your life the way you want to. [It] includes knowing when to recognise the illness limitations and adjusting your way of life to accommodate them ... and living your life to the full. ... The more you live your life and achieve goals, no matter how big or small, that is active self-management.” (Jamie Myers)

What people had to say about their self-management fell under five broad headings:

- 1 Maintaining morale and finding meaning
- 2 Relationships with other people
- 3 An ordinary life: coping
- 4 An (extra)ordinary life: thriving
- 5 Managing ‘having schizophrenia’

The illustration on Page 8 represents the range of themes which participants discussed as part of their approaches to self-management.

The table below shows the themes most talked about by research participants

Top ten themes:

- 1 Occupation, including education, voluntary work, work within the user movement, art and creative occupations, and paid employment
- 2 Relationships with other people, including family and friends and other ‘users’
- 3 Personal qualities, attitudes and beliefs involved in maintaining morale
- 4 Coping strategies for the experiences of schizophrenia
- 5 Managing medication, including managing relationships with prescribers
- 6 Exploring and understanding the experience labelled schizophrenia, including getting information
- 7 Religion and spirituality
- 8 Counselling and psychotherapy
- 9 Complementary therapies
- 10 Healthy living, such as diet and exercise

2. How people are affected by schizophrenia

While psychiatry defines schizophrenia by its symptoms, these are not necessarily the most important problems for the people affected. Participants were invited to say for themselves how they were affected by the condition.

Negative Effects

"It is worse than hell, dying, anything"

While many people described hearing voices, seeing visions, experiencing hallucinations in other senses (touch, smell, etc.), or having periods when they held unusual beliefs, others focused more on the distress of hospital admissions and the side effects of medication.

Others emphasised the social and personal effects, particularly the loss of confidence and the difficulty relating to others.

"It was a horrendous shock, painful, bleak, distressing, I was fragmented and unable to do very much for a long time"

A number spoke of their education being disrupted or losing their jobs or careers. Some lost marriages and homes.

Others spoke of the stigma and the sometimes thoughtless, sometimes cruel, reactions of other people.

Positive effects

A number of people stressed that there were positive aspects to their condition. The creativity associated with the condition emerged a number of times. One person "commanded" his "demons" to write music. Another wrote of

"using negative thinking in a positive manner e.g. in art."
(Robert Hughes)

Other people saw a positive outcome from their struggle to live a life with the condition. One person thought he was

"a much better person for having suffered... many facets of my personality have developed as a result." *(James Wooldridge)*

For all the difficulty and pain of the condition at its worst, most of the participants reported successful self-management in some or most areas of their lives.

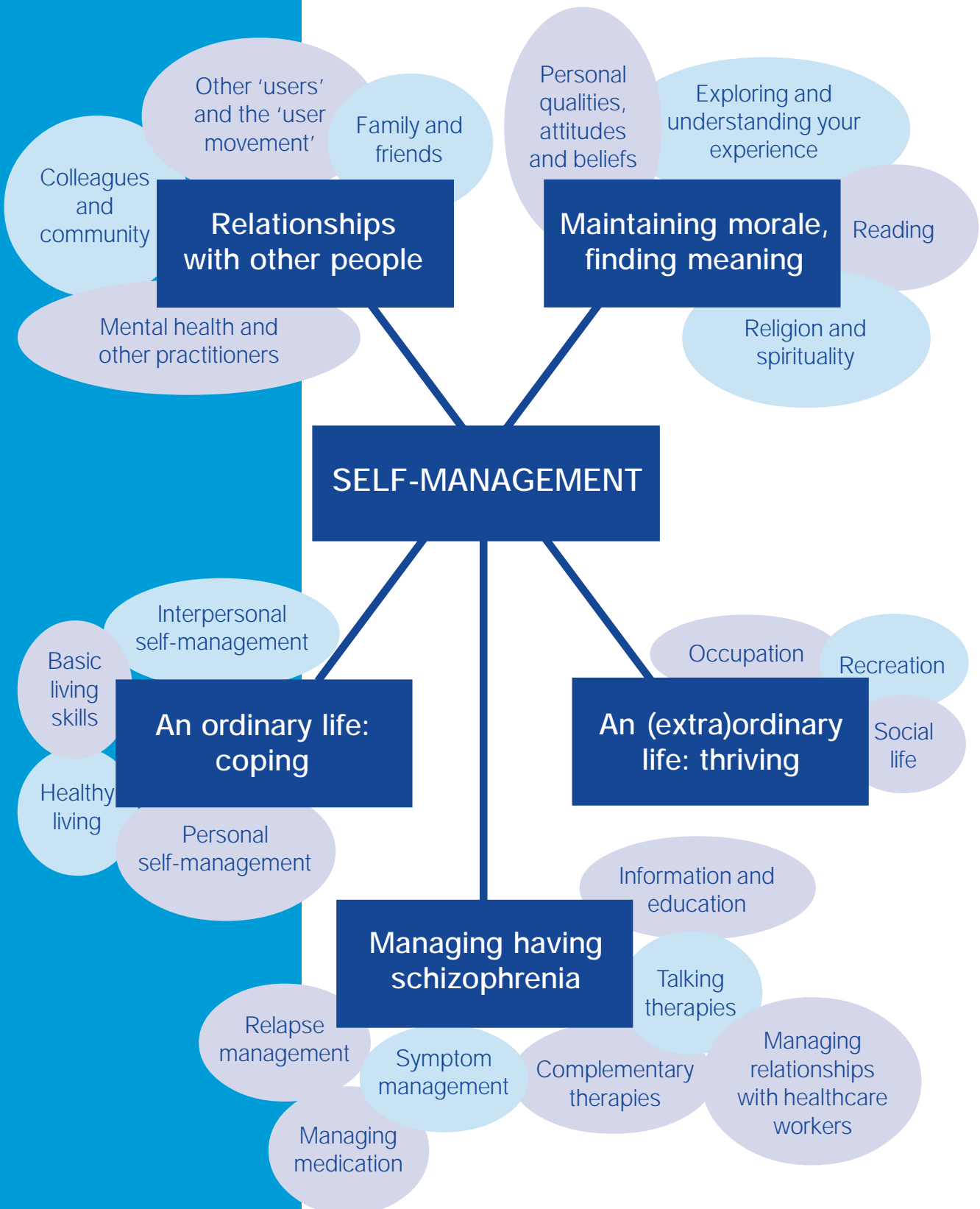
"Anxiety – low self-esteem – depression – panic attacks – poor concentration – thought overcrowding – paranoid thoughts – low assertiveness – prejudice – sensitivity to stress – poor sleep – lethargy – apathy – poor relationships with others – lonely – low self-confidence – anger – frustration – negative thoughts – agoraphobia – fear of water – tranquilliser addiction – confused sexuality."
(Anon)

"Having a feeling for sounds of words – loving music – feeling at one with nature and the universe – being strongly affected by beauty in a positive way"
(Anon)

"The struggle for self-management has been life-affirming. I have become a stronger and even better person. The efforts and achievements of other service users have been inspirational and has given me hope and strength."
(Jamie Myers)

3. Self management in the lives of participants

This section explores the main themes that people reported as significant in their self management.



Maintaining morale, finding meaning

Personal qualities, attitudes and beliefs

Lethargy and apathy, depression and demoralisation, frequently accompany schizophrenia. How did people maintain the positive mental attitude essential to self-management?

Among all the individual differences, the following seemed to be the main factors:

- having hope for a better future
- holding onto goals, ambitions and dreams
- believing that you have some power to affect your situation
- being able to cope with setbacks and slow progress
- accepting your limitations and discovering your strengths and talents
- being prepared to take some risks, while being realistic about what can be achieved.

Exploring and understanding the experience

For many people, coming to terms with their experience, and making sense of it, was an essential part of self-management.

People did this through reading and talking with others. Sometimes this was with a psychotherapist or other professional but, often, talking with others with similar experiences was most helpful. Here one's experiences are totally accepted as 'normal'.

Information about schizophrenia can make the individual's experience less daunting. A number of people spoke of their relief at finding out that their experiences were shared by others, and were not always associated with schizophrenia.

Some wrote to get a handle on their experience. One had written a memoir, others wrote a diary.

Religion and spirituality

Many people's experiences had a spiritual dimension and, for some, self-management included taking up the challenge of understanding the meaning of their experiences.

For some, religious faith helped to maintain morale, and prayer provided a practical tool for enduring difficult times. The church or faith community could be a source of friends and acquaintances.

Religion could also be negative – a source of conflict and guilt, and being excluded by people who did not understand.

"Self-management is a gradual process which takes determination, a positive attitude, goals big and small, and the strength to pick yourself up and keep going when setbacks occur. Doing whatever is important to you strengthens you as a person and maintains your identity."

(Jamie Myers)

"I struggled physically and mentally to make sense of the situation. A war between good and evil was being fought between my ears and I turned to 'The Good Book' often, sometimes pounding my head with it whilst praying fervently."

(James Wooldridge)

Relationships with other people

Relationships with other people were one of the most important factors in participants' ability to self-manage.

Family and friends

Parents and partners or boy/girlfriends were commonly key figures in people's self-management.

Several people spoke of going to live with parents during breakdown or for longer periods (though a few spoke of choosing not to see parents too often, or of being overprotected).

Partners offered emotional support, and practical support at times of breakdown.

A circle of friends who are supportive and non-judgmental offer a buffer against stress.

Some people spoke of the role their children played in their lives.

Other 'users' and the 'user movement'

People found a high level of understanding and acceptance from others with similar experiences and problems.

User groups, self-help groups and day centres provide places to meet people with similar problems and discuss experiences and ways of coping.

"Most of my friends are schizophrenics and that is my choice"
(Chris Andrew)

"The user movement gave support – understood – friendship – compassion – empathy – not judging – liberating – treating you as yourself – listening" (Nina Rideout)

Others

Many spoke of the importance to them of the services they used, be they day centres, supported housing or, for some, day hospitals. A number singled out one or more professionals who had been significant for them.

"My psychotherapist helped me to understand my talents as an artist" (Robert Hughes)

For some, colleagues from work, education and recreational activities provided support; for others, their church or faith community. Other sources of community included the local pub and the Labour Party.

Other people contribute ...

"encouragement
exploration
faith in me
positive expectations
understanding
practical help
inspiration
acceptance
guidance
support"

(Anon)

Hearing Voices Groups can be ...

"... a very important part of coping and self-management as people are able to talk freely and discuss details about the voices that they could not do with their family."
(Chris Andrew)

"...very intimate and family-like. All share their experiences to do with their voices (and) telephone each other to check they are going to be at the meeting"
(Emma Cox)

An ordinary life: coping

Schizophrenia often disrupts people's lives in adolescence and early adulthood. As well as learning to live with the condition, people with schizophrenia often need to catch up on learning they have missed out on.

Basic living skills such as:

- budgeting and "financial discipline"
- finding somewhere to live
- home management
- shopping
- cooking
- personal self-care
- getting medical attention for physical health needs

Healthy living

Exercise, including walking, running, cycling, swimming, gym, yoga and body building, was mentioned by several people. Relief of stress was the most commonly mentioned benefit.

Also mentioned were:

- eating well
- giving up or cutting down on coffee
- giving up or cutting down on alcohol
- not misusing drugs
- getting good sleep

Personal self-management including:

- self-assessment (identifying own strengths and weaknesses, talents and needs)
- goal setting – long term and short term – realistic and manageable
- being organised, planning small steps towards larger goals
- stress management

Interpersonal self-management

A number of participants mentioned that social isolation was a cause or a consequence of a breakdown, and a few reported that learning specific skills or strategies was helpful.

Two people wrote of observing others to learn how to communicate. One spoke of learning to compromise, learning to fit in. Another mentioned learning assertiveness. Withdrawal from social contacts during periods of breakdown was a valuable strategy for some in maintaining social relationships.

"I have had to learn to live on benefits, having previously worked. I cost items and make lists of basic necessities. When shopping I only take the amount of money needed. There is no room for mistakes. I have learned to be very self-disciplined."
(Margaret Howarth)

"Light exercise – such as a daily walk – helps you to feel better physically, counteracts the effects of some medication, and keeps your weight under control. Strenuous exercise – such as swimming – untenses the body and often lifts a lot of headaches and problems almost miraculously"
(Chris Andrew)

An (extra)ordinary life: thriving

“Losing my job was a turning point in my life. I have less stress and anxiety; I’ve got more time to make friends, and I’ve gone from strength to strength”
(Malcolm Hardman)

“Activities in the user movement have provided worthwhile challenges and some satisfaction in life”
(Bob Axford)

“I lost my job and no-one would interview me ... I have become a parish evangelist”
(Rosalind Graham Hunt)

Beyond coping, people sought to build a life which was fulfilling and satisfying. For some the aim was to have a life like other people while others sought to create a life which celebrated their difference.

Occupation

Participants spoke about occupation more than any other issue.

Many people described long personal journeys, perhaps starting with a need to reframe their ambitions in the light of their condition.

One person started a degree three times, finally completing it six years after first starting. He is now working for a Ph.D.

Another did an art foundation course and went on to art college to do a degree. He is now running a community art project.

Another occupied himself for 20 years with artwork, gardening and voluntary work, and now has a paid job for the first time in his life.

Art, writing and other creative activities were a focus for many people. Others took an active role in the user movement. One person spoke at conferences about her experiences. Others organised user groups and networks. Others were involved with campaigning or the provision of mental health services.

Recreation

Reading, writing, painting, sculpting, photography, playing and listening to music, dance, rambling, studying history, were some of the activities that people spoke of.

Watching TV was mentioned by several people. One person described it as “a relaxer” and “a way of getting out into the world”.

Holidays were important for some. One described how going on holiday gave him a sense of achievement and “being on a par with others”. For some people, though, foreign travel was stressful and liable to induce a breakdown. One person paid tribute to the Rethink respite centre, Forresters.

Social life

Having a satisfactory social life is a large part of thriving for most people. See **Relationships with other people** (Page 10) for details.

Managing 'having schizophrenia'

Managing medication

Medication was a major issue for participants in this research. Most had come to accept the need for medication, though many people had stories of side effects such as weight gain, lethargy, Parkinsonism like symptoms, etc.

People had often been through a number of changes of medication. One described his medication management regime as follows:

"Keep steady dose – change when side effects are bad – I have to look after that – down to me to change if things are going wrong.

Long trawl through different types: Chlopromazine – Sulpiride – Risperidone.

Effort to go back to professionals – drug change itself is difficult – have taken time off work to do a drug change (without telling truth – stressful in itself)" *(Laurence Muspratt)*

For some people, the newer atypicals were a great improvement. Others had negotiated being able to self-medicate – increasing their dose within agreed limits at times of stress, and taking a smaller, maintenance dose the rest of the time.

Managing relationships with healthcare workers

Many people had had some good and helpful relationships with professionals, but experiences were mixed.

Complaints included:

- saying that you were getting unwell and not being believed
- being given behavioural treatments that were punitive and damaging
- not being given choice over medication
- lack of guidance on managing hallucinations

People spoke about the importance of being able to communicate with professionals and being able to change the person they were working with if they were dissatisfied. One person spoke of the value of taking responsibility for negotiating the frequency of meetings with his psychiatrist and social worker. Another spoke of learning to criticise and evaluate the explanations and treatments offered, and having the confidence to say no.

"I first asked to go on atypical medication two years ago but was bluffed and passed from pillar to post.

I raised it again and nothing clear was said, no helpful information or discussion regarding choice ensued.

I raised it again with the 'Only the Best'* pack in my hand.

I sat there with the psychiatrist, having all the information before my eyes and before her eyes.

Now I am on an atypical I myself thought looked good on the comparative table in the pack."

(Anon)

* The 'Only the Best' pack is available free from Rethink. Please call 0845 456 0455 for a copy.

“Every breakdown is a valiant attempt at living which has failed”.
(Hermann Hesse, quoted by participant)

“It’s important to face problems and worries at a time when you have the courage to do so (after the breakdown) rather than sticking your head in the sand and saying, ‘The breakdown’s over, I don’t have to change anything.’”
(David Armes)

Relapse management

In the Manic Depression Fellowship programme, relapse management is seen as a central part of self-management.

It did not, however, figure prominently in the responses from participants in this research.

One participant, who did see relapse management as the key aspect of self-management, described his process as follows:

“The first step was to recognise when I was going downhill, and accept I needed to go into hospital before I lost too much control of my behaviour and thinking. A next step was to recognise problems at an even earlier stage and take additional medication, cut down on commitments, and seek medical advice.” *(Bob Axford)*

One participant who had not found a useful approach to relapse management said:

“breakdowns every 3-4 years – seem to just happen – can’t see how to avoid them.” *(Laurence Muspratt)*

One participant focused on another aspect of relapse management: how to get through a breakdown and learn from it. He said:

“I cope by taking extra medication, by withdrawal from social contact, and by going through all the things that are worrying me. Withdrawal prevents me upsetting others and preserves relationships.

Ways of getting through a breakdown are:

- accepting the world as it is, taking a more realistic view
- learning you’ve got to survive
- finding an ability to choose an effective, rather than a psychotic, way of being.

Every breakdown is a learning experience. I evaluate what has contributed to it and develop new coping mechanisms.”
(David Armes)

Another participant described how he strove to identify the vulnerability factors that contributed to his breakdowns, and over a number of years sought to address them.

Symptom management

It would take a much larger study than this to do justice to the range of experiences and ways of coping with them that people with a schizophrenia diagnosis have found. What follows is a brief summary of what was said.

Hearing voices

Some people cope with their voices by giving them a set time each day in which they will talk with them.

Some recognised the voices as coming from themselves, and this made them easier to cope with. This typically comes after a lengthy process of establishing that the voices do not have an external reality.

Others notice that voices are stronger when they are stressed, and they cope by withdrawing from stressful situations.

A number of people belonged to groups where they could share experiences and their ways of coping.

Anxiety, paranoia and panic attacks

Some people talk to themselves to remind themselves that their feelings about the situation are not true. Some avoid situations they feel bad about, but others consider that avoidance may reinforce anxiety. Panic attacks are helped by understanding what is happening, and by breathing and trying to calm oneself.

Other hallucinations

One person described his managing hallucinations as a “lesson in metaphysics”. He had to learn to distance himself from his perceptions and not assume they were true. He compared his approach to meditation in which you watch thoughts arise and pass away without attachment to them.

Talking therapies

Talking therapies were mentioned by a number of people.

Their benefits included:

- an opportunity to explore and understand the experience
- challenging ineffective ways of thinking and acting
- challenging delusory beliefs, paranoia, etc.
- identifying talents and preferred futures
- learning coping strategies
- learning from others in group situations

Complementary therapies

Complementary therapies mentioned included nutrition, Alexander Technique, art therapy, reiki, aromatherapy, acupuncture, meditation and massage.

“Complementary therapies are building up my tolerance to stress, and not just helping me relax. If I had these three times a week I would be able to go back to work. These therapies work alongside medication – I still had psychotic episodes when I was on medication alone. Also, complementary therapies do not dampen emotions as medication does. My zest for life has really come back due to these therapies.”

(Karl Fisher)

4. Building a Self-Management Project

"I am excited by the prospects of the project and what you propose for the future."
(James Wooldridge)

"It is important that the project reaches ... people in day centres, hospitals, those isolated at home ... people who are not already aware of self-management."
(Comment at feedback conference)

"Positive in de-stigmatising schizophrenics, not just from others, [but] mainly from their own worries"
(written feedback to initial report)

"An exciting, emancipatory and path-breaking project"
(Hywel Davies)

"Self-management should be made part of the national curriculum; teenagers should learn about the illness ... when it is first manifest."
(Margaret Howarth)

Rethink is committed to building on the results of this research and developing a project which will support and encourage people with a schizophrenia diagnosis to self-manage as far as possible.

Research participants offered many ideas as to what form such a project might take.

Many people testified to the help they had received from sharing experiences and ideas with others with similar experiences, and proposed self-management support groups, either user-led or co-led with a skilled facilitator.

One-to-one peer support, or mentoring by a more experienced self-manager, was also proposed.

There was strong support for written material on self-management, for use both by individuals and groups.

The use of the internet was suggested, both as a place to publish information about self-management, and for the provision of a support group or chat room.

The most common interest was in how other people coped with their symptoms. There was also a thirst to hear about people who had had schizophrenia and recovered.

There was concern that the self-management project should be available to everyone – that it should reach people with more severe difficulties, in hospital and supported housing.

Participants also wished to see the project remain as far as possible user-led, and to ensure that self-management was not co-opted to become just another way of being managed by others.

Rethink is currently looking at the best ways to implement these ideas and will be seeking funding to begin pilot projects during 2004.

5. Self-Management Initiatives

Chronic Disease Self-Management Course (CDSMC)

www.stanford.edu/group/perc/cdsmp

www.lmca.org.uk

Developed by Kate Lorig at Stanford University and promoted in Britain by the Long-Term Medical Conditions Alliance (LMCA).

It is a generic self-management course – i.e. it is designed to address issues experienced by people with *any* chronic condition – but it has been most used by (and is perhaps most useful for) people with physical conditions.

It is a six-session programme, led by people with experience of self-managing a long-term condition. At its core is a problem-solving, action-planning approach, which encourages participants to have confidence in their ability to make a difference to their own situation. Mutual support is also emphasised.

Instruction is given in dealing with common physical symptoms and emotional consequences of long-term illness, in taking treatment decisions, and in communicating with health professionals.

Expert Patients Programme

www.ohn.gov.uk/ohn/people/expert

The NHS is introducing user-led self-management programmes as part of a move to encourage a more equal partnership between patients and healthcare providers.

Initially, the NHS is using the generic CDSMC (see above) adapted to UK needs. A module addressing mental health-specific issues will be added when required.

As the programme develops, more condition-specific self-management programmes may be adopted if there is evidence that they are more effective.

Hearing Voices Network (HVN)

Hearing Voices Network (HVN) promotes an approach to hearing voices based on the work of Marius Romme. Romme discovered that a large number of people heard voices without needing to use psychiatric services. People had a variety of explanatory frameworks for the phenomenon and for some it was a positive experience.

HVN encourages self-help groups (and individuals working with a supporter) where voice hearers can talk about their experiences and develop strategies for coping with the negative effects of hearing voices.

While HVN does not use the language of self-management, this is an effective self-management approach for some people.

Chronic Disease Self-Management Course (CDSMC)

www.stanford.edu/group/perc/cdsmp

www.lmca.org.uk

Expert Patients Programme

www.ohn.gov.uk/ohn/people/expert

Hearing Voices Network (HVN)

Self-Management Initiatives cont.

Manic Depression Fellowship Self-Management Training Programme

www.mdf.org.uk

Manic Depression Fellowship Self-Management Training Programme

www.mdf.org.uk

Running since 1998, this is based on the experiences of people with manic depression and informed by the work of Mary Ellen Copeland (see WRAP, below).

A programme consists of six sessions, facilitated by two user-trainers. Four follow-up days in the following twelve months are available for ongoing support.

The programme is built around three themes:

- 1 Recognition: includes triggers, warning signs and using a life chart
- 2 Action: creating an action plan, coping strategies, self-medication and support networks
- 3 Maintenance: includes crisis management, advance agreements and lifestyle choices.

National Voices Forum

www.voicesforum.org.uk

National Voices Forum

www.voicesforum.org.uk

National Voices Forum is the user and survivor network within Rethink. It has a long-standing involvement in self-management. It has been running annual self-management conferences since 1998 and members have supported the Rethink Self-Management Project as participants and members of the steering group.

Strategies for Living

www.mentalhealth.org.uk

Strategies for Living

www.mentalhealth.org.uk

Strategies for Living, based at the Mental Health Foundation (MHF), is a programme of user-led research into what enables people with mental distress to live a full life. Their publications are an invaluable resource for people interested in self-management.

Wellness Recovery Action Planning (WRAP)

www.mentalhealthrecovery.com

piers.allott@wlv.ac.uk

Wellness Recovery Action Planning (WRAP)

www.mentalhealthrecovery.com

Based on Mary Ellen Copeland's personal journey of recovery from depression and manic depression, WRAP combines a focus on developing a 'wellness toolbox' – activities (and avoidances) which maintain well-being – with planning ahead for periods of illness through self-awareness of triggers and early warning signs, and writing a crisis plan.

Accredited WRAP trainers in Britain may be contacted through Piers Allott at piers.allott@wlv.ac.uk.

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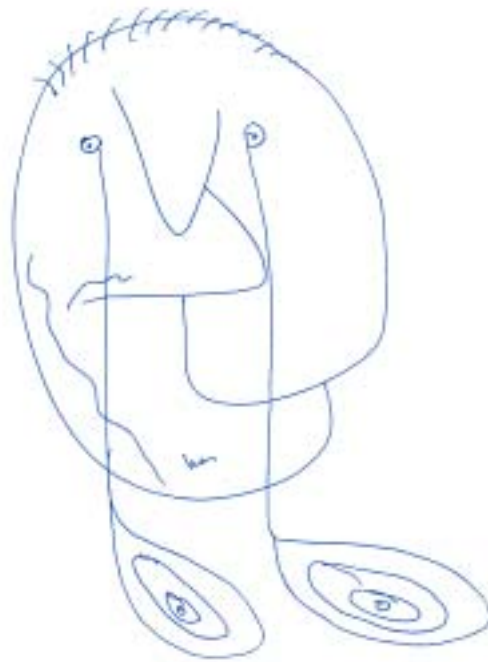
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“Allowing myself to feel bad can also be a self management strategy”
Anon

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Registered office:
28 Castle Street
Kingston upon Thames
Surrey
KT1 1SS.

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