Running On Empty

Building Momentum to Improve Well-Being in Severe Mental Illness

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rethink severe mental illness

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LILLY IS PLEASED TO SUPPORT THE PRODUCTION AND LAUNCH OF THE *RUNNING ON EMPTY* REPORT.

Painting the Picture

“Diagnosed with schizophrenia, I frequently hear voices and believe that people are conspiring against me. I am extremely self-conscious about the way I look and often find it difficult to leave my house.”

“Suffering from psychotic illness, I used to live a miserable existence, my mental health condition deteriorated and I was hearing voices constantly. I harmed myself on a regular basis, by severely cutting or burning myself.”

“Living with schizophrenia and acute anxiety, I am fearful of public transport and am unable to travel to work.”

“Living with manic depression has been a debilitating experience for close to seven years now. Bipolar disease affects how one feels about their surroundings and one’s life and can leave a person vulnerable to a loss of self-esteem and a will to live. I have felt like my life has had no other purpose but to take pills to balance the chemicals in my brain, to attend the outpatient appointment and avoid hospital admissions.”

“I am a warm and friendly person but am bullied and taken advantage of because of my mental illness.”

“I lived an isolated life, withdrawn, acknowledged by no-one and completely neglected in my personal appearance.”

At some point in their life, as many as two in a hundred people in the UK alone will experience severe mental illness[1,2] and millions of people around them – be they family members, carers or healthcare professionals – will also be affected. In order to gain some level of appreciation for what it is like to live with a severe mental illness, it is important to understand how those affected by symptoms view their own experiences and feelings.

Introduction

Severe mental illnesses are generally seen to be those in which psychosis is likely to occur and, as such, the term "SMI" is used by many healthcare professionals to describe those living with schizophrenia or bipolar disorder. In reality however, it is perhaps not as simple to define these conditions using such terminology. For example, the prognosis for both illnesses are very different and generalisations about SMI based on people's experiences with schizophrenia could potentially exclude those with bipolar disorder or visa versa. Also, because a person with a mental illness, such as depression, does not experience psychosis, this does not mean that their condition is any less serious.

The *Running on Empty* report has been developed to highlight the currently unmet needs and issues pertaining to those living with schizophrenia and bipolar disorder under the umbrella term of SMI.

People who experience SMI are being increasingly recognised as a particularly health-compromised group because of a number of different factors which combine to put them at much higher risk of developing major physical health issues such as cardiovascular disease and type 2 diabetes than the general population.[3,4] In order to manage these risks as well as look after the mental health-related aspects of their condition, it is important to ensure a holistic approach to care is undertaken. At present, despite the wealth of clinical information, government guidance and programmes for those with SMI to proactively engage in their own care, research has shown that there is often a failure by health services to adequately deliver this approach.[5,6]

A number of positive steps have been made to improve this situation. Based on extensive research and opinions gathered from healthcare professionals delivering care, charities and those living with SMI, this report aims to outline the current scale of the problem, review the level of care currently being provided and recommend a series of solution-driven approaches that can be realistically and practically adopted to tackle the issues being faced.

Executive Summary

In the UK, two in 100 people will experience severe mental illness (SMI) at one time in their life.[1,2] In addition to mental health problems, those living with SMI are also significantly more at risk than the general population of developing major physical health-related issues as a consequence of their illness itself, the lifestyle they are often forced to lead because of their socio-economic circumstances and the way their condition is managed by the healthcare profession team.

Significantly higher incidences of cancer, cardiovascular disease, type 2 diabetes, obesity and HIV/AIDS translate into rates of premature death which are up to three times higher than the general population.[3] On average, those with SMI die between ten to 15 years earlier.[4] In order to address these physical health issues, there is an urgent need to ensure that a holistic, supportive, choice-driven approach is widely adopted into the everyday provision of care and delivered by all healthcare professionals. This approach aims to support people affected by SMI to improve their quality of life and therefore reduce the inevitable mortality rates.

Despite this need being well-documented in clinical research and numerous government guidelines directing how care should be delivered, recent survey data collected for the *Running on Empty* report suggest that only around half of GPs provide lifestyle advice on healthy eating, weight management or exercise.[5] Another survey run in parallel, reveals that many of those affected by SMI are often not having routine assessments such as blood pressure and blood glucose tests or are not being provided with weight management or lifestyle advice.[6]

In light of this, the *Running on Empty* report has been developed by a group of 14 multi-disciplinary healthcare professionals, six charities and professional organisations. to review the issues faced by people with SMI, assess the influences on health care practice and present a series of recommendations to improve the provision of care and help instil an improved level of confidence amongst those living their lives with severe mental illness. The following call to action has been set-out.

A Call to Action

- The healthcare professional team should strive to address all the health-related issues experienced by those with SMI with a holistic approach that takes into account the entire well-being (physical and mental health and lifestyle) of the individual. Failure to do so can have a serious effect on quality of life and ultimately, may even lead to premature death
- The aim of therapeutic intervention – undertaken on an individual basis through two-way consultation with those in care – should be to allow the mental state of those with SMI to be effectively stabilised so that they can begin to proactively become engaged in their own overall well-being in partnership with their healthcare professional
- Although at times, those with SMI may be difficult to engage, their rights to a supportive, choice-driven and integrated programme of care must not be compromised during any stage of the care

> *"The fluctuating nature of serious mental illness can lead people to neglect their physical health, which may in turn further diminish their quality of life. SANE has long called for a holistic approach to serious mental illness, and we welcome this report, which highlights the need for the physical health of people with serious mental illnesses to be fully catered for."*
>
> ***Marjorie Wallace MBE, Chief Executive, SANE***

Contributors

John Abbott

John is the Public Affairs Manager for Hafal, a leading client-led Welsh mental health charity, supporting 650 people with severe mental illness, their families and carers every day throughout Wales. John is a member of the Wales Alliance for Mental Health in Primary Care, the Wales Collaborative for Mental Health, Innovations in Care and the Wales Carers Alliance.

Hafal employs over 100 staff and 60 client-led projects across Wales with a Head Office based at Llandarcy, Neath. Hafal campaigns vigorously on behalf of those with severe mental illness, their families and carers; all Hafal's services are underpinned by an innovative and holistic Recovery Programme.

Paul Corry

Rethink severe mental illness is a membership-based campaigning charity that manages 400 services in England and Northern Ireland. It is working together to help everyone affected by severe mental illness recover a better quality of life. Charity number 271028. Paul Corry is Director of Campaigns and Communications.

Elizabeth Gale

Elizabeth is the Director of **mentality**, the first national team dedicated solely to the promotion of mental health, based at the Sainsbury Centre for Mental Health. Elizabeth is one of the founding members of **mentality**, established in 2000. **mentality** provides policy advice, training, support, consultation and resources to promote public mental health and well-being . It has a network for mental health promoters and works throughout the UK.

Elizabeth has worked in mental health for over twelve years. She has written extensively on the physical health needs and health promotion needs of people with mental health problems at **mentality** and the Health Education Authority.

Stephen Gough

Stephen Gough is a Professor of Medicine at the University of Birmingham and a consultant diabetologist at University Hospital of Birmingham NHS Foundation Trust, Selly Oak Hospital. He trained at Leeds University Medical School, where he later returned after a series of junior doctor posts to pursue a research interest in type 2 diabetes and cardiovascular disease risk factors and gain his MD. His research career developed as MRC lecturer at the University of Oxford where his interests moved into the genetic basis of type 1 diabetes and related conditions. He has continued with this theme of research in Birmingham where he also has a clinical interest in diabetes and its complications, specifically diabetic foot disease.

Kevin Gournay

Kevin is a Chartered Psychologist and a Registered Nurse. He combines clinical work with research and has projects in Australia, Russia and several other countries. He is the author of 300 books, monographs, papers, chapters and major conference papers. He has other responsibilities in mental health including chairing the NICE panel on the management of violence, being an expert witness on PTSD and suicide, working for the Joint Parliamentary Committee on Human Rights and conducting policy work for the Department of Health. He is President of No Panic (the UK's largest anxiety self help group). In 2004 he was elected as Psychiatric Nurse of the Year by the American Psychiatric Nurses Association.

Richard Holt

Richard Holt trained at the University of Cambridge and the London Hospital Medical College. He undertook his post-graduate training in diabetes and endocrinology in the South East Thames Region. Richard's current research interests are broadly focussed around the pathogenesis of the insulin resistance syndrome. These encompass studies of the effects of severe mental illness on diabetes, the developmental origins of adult diabetes and cardiovascular disease, and the effects of the adult environment – in particular the benefits of physical activity and risk of obesity.

Ian Hulatt

Ian Hulatt is the Mental Adviser at the Royal College of Nursing. He has a UK remit and is responsible for advising on the RCN's contribution to Mental Health Nursing policy. He supports the work of the four member led forums in Mental Health within the RCN , and liaises with individual RCN members who seek support in their work. Prior to this role he was a lecturer in Mental Health Nursing for seventeen years teaching both undergraduate and post graduate nurses. This latterly was focussed on the leading of a Thorn (psycho-social interventions) course. Based primarily in Wales Ian's role involves much travel which affords the opportunity to encounter much good practice in the craft of Mental Health Nursing.

Annette Jones

Annette Jones was appointed to the role of Nurse Advisor for the Well-Being Support Programme in February 2003. Prior to this she, along with a colleague, set up the Crisis Assessment Service in Prince Charles Hospital which had an impact on the amount of referrals/assessments at the Acute Psychiatric unit. Qualifying as an RMN in 1996, Anette has worked in EMI, acute and Community settings. She has always been interested in new and innovative ideas and this role was the perfect opportunity to help people who have SMI to seek help to improve physical health and lifestyle.

Chris Manning

Dr Chris Manning was an NHS GP until 1999, when he took early retirement on health grounds, having had major depression since 1986. He works in the mental health voluntary sector with Depression Alliance and Primhe (Primary care Mental Health and Education); the latter as its founder-CEO. He serves on the national mental health taskforce and the NIMHE advisory boards on mental health promotion and anti stigma and discrimination. His core value in life is "Nothing is impossible if people do not have to claim the credit for it."

Ian McPherson

Dr Ian McPherson took up post as Director of the West Midlands Development Centre for the National Institute for Mental Health in England (NIMHE West Midlands) in October 2002. A Clinical Psychologist by professional background, Ian worked as a practitioner, researcher and trainer, before moving into service development and management. He then had 9 years of Board level responsibility as Director of Mental Health in two large Community Trusts. Through this he gained significant experience of managing change in the delivery of services, in reconfiguring and integrating health and social care organisations and in improving links between primary care and specialist services.

He has a longstanding clinical and research interest in dealing with mental health problems in primary care and in improving the quality of experience of people using services at that level. Within NIMHE he has been joint lead Director for the Primary Care Mental Health Programme.

John Pendlebury

John completed his basic nurse training nearly 30 years ago and started working as a Community Psychiatric Nurse (CPN) in 1984. He has completed courses in behavioural psychotherapy, community psychiatric nursing, and a Postgraduate Diploma and Master of Science degree in Practitioner Research. John has spent most of his time working in the community. At the request of several of his patients, he set up a weight management clinic at Cromwell House in May 2000. He has a special interest in the general physical health issues associated with severe mental illness.

Robert Peveler

Robert Peveler is currently Professor of Liaison Psychiatry and Head of the Mental Health Clinical Group at the University of Southampton, where he has worked for twelve years. He is also an honorary consultant in the Hampshire Partnership NHS Trust. He previously held posts as Wellcome Trust Research Fellow and Clinical Lecturer at the University of Oxford, where he trained in medicine and psychiatry. Before embarking on his clinical career he completed a doctorate in cardiovascular physiology. His clinical work is in liaison psychiatry, with particular interests in chronic pain and fatigue. He teaches and researches on the topics of psychological problems related to physical illness, medically unexplained symptoms, and the detection and management of common mental disorders in general health care settings. He also has a research interest in self-care in chronic disease and adherence to treatment. He has published many papers and chapters in these fields, and recently co-edited a book on planning specialist services in liaison psychiatry. He is on the editorial board of the Journal of Psychosomatic Research. He is a past member of the Primary and Community Care and Pharmaceuticals Panels of the UK Health Technology Assessment Programme.

Michelle Rowett

Michelle Rowett is Chief Executive of the Manic Depression Fellowship, the national user-led organisation for people who are affected by manic depression (bipolar disorder). She has been Chief Executive since 2000, although she has been with the Fellowship since 1994. During this time, the Fellowship has more than doubled its turnover, trebled its staff and gained a reputation for innovative work in enabling people affected by manic depression to gain control over their lives.

Prior to joining the Fellowship, she worked for the Charity Commission. Michelle has a degree in History, and has completed the Open University postgraduate certificate in voluntary sector management.

Gary Sullivan

Gary graduated from Medical School in Cardiff in 1982, and did GP training in the Welsh Valleys, obtaining the MRCGP in 1986. He then changed track and trained as a psychiatrist in South Wales, obtaining MRCPsych in 1993. He was appointed as Consultant Psychiatrist in North Glamorgan NHS Trust in 1997, Clinical Director for Mental Health since 2000 and External Professor of Psychiatry at the University of Glamorgan in 2004. His current research interests include Mental Health service development, and Liaison Psychiatry.

Jogin Thakore

Jogin holds a dual appointment, as a Clinical Psychiatrist at the Neuroscience Centre, St. Vincent's Hospital, Fairview, and as a Senior Lecturer in Psychiatry in the Department of Psychiatry at the Royal College of Surgeons in Ireland. His alma mater is Trinity College, Dublin (MB, Bch, BAO, BA) and his training was initially in Ireland though went to London early in his career where he obtained his Psychiatric Membership (MRCPsych) and a PhD in Psychiatry with the University of London. On returning to Ireland he was awarded

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membership of the Royal College of Physicians of Ireland (MRCPI). His principal area of research is to examine metabolic, stress axis, neurophysiological and metabolic changes, in those suffering from schizophrenia. Jogin and his team collaborate with Dermot Kenny in Clinical Pharmacology at the Royal College of Surgeons in Ireland. They have set up a laboratory which will measure Evoked Related Potentials at St. Vincent's Hospital in collaboration with John Foxe at the Nathan Kline Institute and Ian Robertson at the Trinity College Institute of Neurosciences.

Andre Tylee

Professor Andre Tylee worked for twenty years as a general practitioner in South London developing his practice from being single-handed when he arrived to having four partners, two trainee doctors and two salaried doctors when he left to take up the first Chair in Primary Care Mental Health in the world in 2000. The Chair and Section of Primary Care Mental Health is based at the renowned Institute of Psychiatry, Kings College, London. Professor Tylee runs the Primary care R+D programme for the Institute of Psychiatry and the Maudsley Hospital which is rated as strong by the Department of Health.

Professor Tylee also chairs the Primary Care Programme of the National Institute of Mental Health in England (NIMHE) which runs national programmes on commissioning, core skills training, leadership, user empowerment, Research and Development, Workforce (new workers) and Integrated care. He also invented the internationally acclaimed "Trailblazers" teach the teacher programme which has over 400 graduates in England and is being started in the USA, New Zealand and Australia in 2005. He hold an honorary Chair at Monash University, Melbourne. He edits Primary Care Mental Health Journal and advises numerous mental health charities. He has published widely in journals and textbooks, mainly on the recognition and management of depression in primary care.

Marjorie Wallace

Marjorie Wallace, MBE, is the Chief Executive of SANE UK and an award-winning investigative journalist, author and broadcaster who has worked with ITV and the BBC as a reporter and film director. As founder and Chief Executive, her responsibilities include mental health campaigning activities, The Prince of Wales International Centre for SANE Research, for which she raised £6 million, and SANELINE. Marjorie has received a BA in psychology and philosophy, an Honorary Doctorate of Science from City University, an 'Award for Public Service' from the British Neuroscience Association and is an Honorary Fellow of the Royal College of Psychiatrists. The Daily Mail cited Marjorie as one of 'Britain's 100 most influential women' in 2003 and SAGA Magazine readers voted her as the 3rd "Wisest" person in 2005.

Elaine Weston

Elaine Weston has a BSC in Pharmacy from De Montfort University where she studied from 1976 – 79. She joined St James University Hospital Leeds as a post graduate student and was appointed as a resident on-call pharmacist for three years before taking up her post as Staff Pharmacist for Meanwood Park Hospital (Learning Disabilities) in 1983. Following this, she conducted sessional work for Leeds North East PCT and enjoyed several different posts in Leeds including Community services Pharmacist, Patient Services Manager at St James University Hospital and latterly Post Graduate Pharmacist manager at Leeds Acute Hospitals Trust. Since 2002 she has been appointed as the Chief Pharmacist at Leeds Mental Health Teaching Trust. Elaine is a member of the UK Psychiatric Pharmacists Group.

David Yeomans

Dr David Yeomans is a psychiatrist in Leeds and an honorary senior lecturer at the University of Leeds. He lectures and writes on examination techniques for postgraduate doctors. He set up and works in the innovative multi-agency mental health service, CHOICE (recently described in the Health Service Journal). He has been a lead consultant in the Well-Being Support Programme – a national programme of systematic health improvement for people with severe mental illness. He has seen at first hand the benefits of actively engaging people with the Well-Being Support Programme. These include early detection of potentially fatal illnesses and effective reduction in cardio-respiratory risk factors such as being overweight, smoking and inactivity. Other gains reported by service users are improved self-esteem, better understanding of their own health and enjoying the non-mental health focus in their care plans.

Professor Allan Young

Professor Allan Young trained in medicine and thereafter psychiatry at the University of Edinburgh and held a Royal College of Physicians of Edinburgh training fellowship at the MRC Brain Metabolism Unit. Subsequently, he was a clinical lecturer at the University of Oxford and the MRC Clinical Psychopharmacology Unit. Currently Professor of General Psychiatry, Allan Young is also Director of both Psychiatry and the Stanley Research Centre at the University of Newcastle upon Tyne, and Head of the Academic Mental Health Unit. He is a Council Member and Secretary of External Affairs of the British Association for Psychopharmacology; Secretary of the Royal College of Psychiatrists' Psychopharmacology Special Interest Group; Member of the Executive Committee, Faculty of General and Community Psychiatry, Royal College of Psychiatrists; and a member of the Scientific Advisory Council of the Stanley Medical Research Institute. He has published extensively on the aetiology and treatment of psychiatric disorders, particularly mood disorders.

Section 1: The Scale of the Problem

"Well-being does not begin and end with a person's mental state – all aspects of health are important. Our aim should be to achieve a balance between controlling mental state with medication and other therapies and taking account of all other aspects of health."
Professor Robert Peveler, Professor of Liaison Psychiatry, University of Southampton

Prevalence of Severe Mental Illness and Major Physical Health Issues

At some point in their life, as many as two out of a hundred people in the UK alone will experience SMI and millions of people around them will be affected.[1,2] Unfortunately, those affected by SMI – namely those with schizophrenia and bipolar disorder – will not only experience a wide range of symptoms related to their mental health, but will also be affected by physical well-being issues which can translate into premature rates of death that are up to three times higher than the rest of the population.[3]

Some of the most common well-being issues for people with SMI include: cardiovascular disease, obesity, type 2 diabetes, sexual health problems, stroke, osteoarthritis, hyperprolactinaemia, dental problems, HIV/AIDS, hepatitis C, respiratory problems, irritable bowel syndrome and some cancers.[3,4,7,8]

- **Cardiovascular Disease**
  The prevalence of cardiovascular disease (CVD) in people with SMI, is known to be higher than the general population.[3,4] In people living with schizophrenia, CVD is the single largest cause of mortality amongst males and females.[9] A recent study of those undergoing long-stay psychiatric care found that 48 per cent of males and 9 per cent of females may also be at risk due to hypertension.[10] Mortality due to ischaemic heart disease, cardiac arrhythmias and myocardial infarction is also higher in people with SMI.[3,4]

- **Weight Gain and Obesity**
  Weight gain is common among people with SMI. In a hospital sample of those undergoing long-stay psychiatric care, 36 per cent of men and 75 per cent of women were shown to be obese, compared with rates of 17 per cent in men and 22 per cent in women amongst the general UK population.[10] Reasons for this increase may be due to a combination of lifestyle and medication which are both addressed later in the report. Whilst the latter may be associated with an undesirable degree of weight gain, there are marked differences in the extent of weight change observed between individuals.

- **Type 2 Diabetes**
  Many studies have reported that impaired glucose tolerance and insulin resistance are more common amongst those living with SMI than the general population.[3,4] Type 2 diabetes has also been found to be up to 5 times more common in those with SMI, in comparison with the general population.[11,12]

"Diabetes is not being picked up early enough through rigorous screening across the board. In addition, people with SMI may also find it harder to access healthcare because of their condition."
Dr Richard Holt, Senior Lecturer in Endocrinology and Metabolism, University of Southampton

This suggests that an intrinsic risk between diabetes and SMI may exist. Although this relationship requires additional clinical research to prove, it is likely to be predominantly genetic and environmental with other potential factors including some possible effects of medication also playing a role.

"Current research suggests a genetic link between diabetes and schizophrenia. Typically, up to 30 per cent of people with schizophrenia have a family history of diabetes, which is significantly higher than the general population."
Dr Richard Holt, Senior Lecturer in Endocrinology and Metabolism, University of Southampton

- **HIV and AIDS**
  The incidence of HIV/AIDS in people with schizophrenia, is estimated at between four and 23 per cent – a much higher figure than that seen in the general population.[3] Connected factors may be the higher rates of unsafe sex practiced with multiple partners and intravenous drug misuse which often occur amongst those affected by SMI.[3,7] In addition, sexual exploitation of these vulnerable individuals (especially those with schizophrenia) who live in group situations – such as group care homes, hostels or on the street, is also common.[7]

Section 1: The Scale of the Problem

> *"When people are unwell, their judgement may be impaired and they may behave in a way that they would not contemplate ordinarily. For people with bipolar, when they are high, they may become sexually disinhibited with all the potential consequences this might bring."*
> ***Michelle Rowett, Chief Executive, MDF The BiPolar Organisation***

- **Cancer**
  People with schizophrenia are more likely to develop cancer, largely related to the poor lifestyles they adopt. In addition, if affected by the disease they have a 50 per cent lower chance of survival.[3] Differences exist for individual cancers in people with mental illness. Women with schizophrenia are at an increased risk for breast cancer, and gastrointestinal and pancreatic cancers are more prevalent in SMI.[3,7]

- **Sexual Health Problems**
  People with SMI are more likely to experience sexual health problems than the general population often due to a lack of access to appropriate healthcare guidance, a lack of awareness about the regular checks they should be receiving.[7,8]

Factors Leading to Poor Physical Health

> *"The literature associating poor physical health to SMI dates back for years."*
> ***Professor Kevin Gournay CBE, Head of Psychiatric Nursing, Institute of Psychiatry, London***

Whilst there are no definitive explanations as to why those living with SMI are more prone to long-term physical health issues than the general population, in addition to the intrinsic risk factors, there are also a number of social factors which may hinder access to appropriate provision of care for those with SMI.

In comparison to the general population, recent research from The Royal College of Psychiatrists in 2003 shows that the numbers of people out of work with a diagnosis of severe mental illness rise as high as between 60 – 100%.[13] In isolation, this is a clear indicator for poor health and diet but the addition of SMI to the equation can further hamper the opportunity to make lifestyle changes. Consequentially, when again compared to the general population, smoking, alcohol consumption, substance abuse, poor diet, and a lack of exercise tend to be more prevalent amongst those with SMI.[3,4,7,14]

> *"People who are not mentally stable do not generally tend to look after themselves well. For financial reasons and convenience they tend not to adopt a healthy diet and often lead sedentary lifestyles due to the negative symptoms associated with their disease."*
> ***John Pendlebury, Community Psychiatric Nurse, Salford***

Recent 'real-life' survey data collected during market research[6] designed to support the development of this report, further reinforce the above:

	Survey Respondents	UK National Average
Smokers (%)	41	26
Fruit and vegetables (portions/day)	2.1	3.3
Exercise (minutes/week)	49.4	98.0

Cigarette smoking is especially common among people living with SMI.[3,10,15] It is often viewed as a method to improve concentration, reduce boredom, negate feelings of anxiety and to diminish negative and extra pyramidal symptoms.[7] It has been shown that between 62 per cent and 81 per cent of people with schizophrenia smoke tobacco compared with 25 per cent of the general population[1,4] and 50 to 90 per cent are nicotine dependent.[7] This increased rate inevitably leads to a higher rate of tobacco-related fatal disease. [3,10,14,15]

> *"We need to look for points of opportunity where those with long-term mental illness may want to act to improve their physical health. We also need to be willing to provide long-term support. If someone with schizophrenia has smoked for the past 30 years it may take some time for them to be able to stop."*
> ***Professor Robert Peveler, Professor of Liaison Psychiatry, University of Southampton***

Alcohol and drug abuse are also a considerable problem in the SMI population. Nearly 35 per cent of those living with schizophrenia abuse alcohol at some point in their lives, even though alcohol use can worsen psychotic symptoms and medication side-effects, such as extra pyramidal symptoms.[7] The UK figures for drug and alcohol problems in individuals with SMI show that over the course of a year, 36 per cent have some form of substance misuse problem and when broken down, 32 per cent of these account for alcohol dependence and 16 per cent for drug problems.[16]

"Research indicates that you simply do not live as long with SMI as you do without. In addition to lifestyle, diet issues and medication, many of those affected self-medicate to control their anxiety with alcohol, nicotine and cannabis."
Ian Hulatt, Mental Health Adviser, Royal College of Nursing

Between 15 per cent and 60 per cent of those with schizophrenia also abuse psychoactive drugs such as cocaine, which is a higher number than among those of the general population.[7] As expected this can lead to a lack of compliance with treatment, resulting in a heightened risk of relapse.[7]

"There is current emphasis on recovery from SMI. Secondary to this is physical health care and lifestyle management. You can not separate mental and physical health in such a fundamental way. For us not to recognise this, we are not providing a holistic approach to care and are providing a disservice to people with SMI as we need to look at treating the whole person."
Elizabeth Gale, Director, mentality

The Role of Medication

Severe mental illness is a condition that normally requires long-term medication. The aim of therapeutic intervention with medication is to allow the mental state of those with SMI to be effectively stabilised so that they are better able to reintegrate into society and lead normal lives. However, all medicines vary in their level of effectiveness on an individual basis and are potentially associated with a range of side effects. The *Question of Choice* survey, undertaken jointly by MIND, Rethink and the MDF The BiPolar Organisation found that the most prevalent physical side-effects of antipsychotic medication were weight gain (62 per cent) and effects on the eyes (38 per cent).[17]

"All medication can be associated with side effects, but by simply switching treatment this does not ensure those taking the medication will not experience the same side effects or indeed develop new ones."

"When people are mentally well and stable on a medication, when you change treatment you run the risk of destabilisation as a result and therefore render the individual more incapable of tackling lifestyle issues."
John Pendlebury, Community Psychiatric Nurse, Salford

Recent studies suggest that effectiveness is one of the most important aspects to consider when choosing a medication.[18] Those with SMI often require long-term maintenance treatment for their condition and therefore relapse prevention and restoration of social function are considered to be the most important results of successful therapy.[18] Both of these outcomes are inextricably linked to efficacy of treatment.

"People with SMI are treated with medication for a long duration of time, potentially indefinitely. It is these individuals who require greater management for their illness because their overall physical and psychiatric well-being is most at risk."
Dr Richard Holt, Senior Lecturer in Endocrinology and Metabolism, University of Southampton

"A proactive approach to medication side-effects should be taken, not just monitoring the effects but dealing with them."
Dr David Yeomans, Consultant Psychiatrist, University of Leeds

Although medication may have side effects, it is not always advisable to switch treatment if it is effective and associated

Section 1: The Scale of the Problem

with a low risk of relapse. If SMI is managed through effective symptom reduction, people with SMI are better placed to undertake a well-being approach and actively choose to work on those areas of their life requiring attention. Those taking medication should also be made aware of any potential side-effects and provided with information on how to manage and minimise the effects should they occur.

However, should the side-effects of any given medication be considered unacceptable by either the individual taking or those prescribing therapy, alternative options should always be discussed and attempted. It is only through these discussions that improved relationships and levels of trust can be fostered between the healthcare professionals and those in their care.

"All drugs have side effects therefore it is not only a question of ensuring well-being is looked after in every person receiving treatment, but to improve medication management as well. Those under care should be warned in advance of treatment, the side-effects they may expect and be helped to manage these side-effects."

Professor Kevin Gournay CBE, Head of Psychiatric Nursing, Institute of Psychiatry, London

"Physical health checks and help to manage side-effects are often not being provided in the first place. They need to be built into regular reviews of medication that give people the right to an informed choice about the options that enable them to optimise their quality of life and a sense of physical and mental health well-being."

Paul Corry, Director of Campaign and Communications, Rethink

"The side effects of drugs have to be balanced against the benefits achieved through an improved mental state. As such, efficacy should guide medication choice rather than possible side effects. Through healthy lifestyle programmes it is possible to obviate a lot of the potential side effects."

Dr Richard Holt, Senior Lecturer in Endocrinology and Metabolism, University of Southampton

Provision of Care

When symptoms of SMI such as cognitive impairment, social isolation and a suspicion of the care provider (often driven by past experiences including sectioning, forced medication and personal views being ignored, dismissed or suppressed) combine to leave an individual with SMI disinclined to seek care, or not continue their treatment as directed, provision of good care is significantly diminished. In many instances this is not the fault of those affected by SMI and as such, healthcare professionals must engage "the whole person" in discussions about their care. In addition, a lack of social skills may also preclude those affected from being able to effectively communicate clearly about a medical problem and even when they do, they may not be able to accurately convey their symptoms due to difficulties in expressing their needs.[19] Research supports this, showing that those living with schizophrenia are less likely than people without to report physical symptoms spontaneously.[20]

"People with SMI are too often ignored when they present with a physical health issue. Health services are often not sufficiently geared up to listen to a person as they would anyone else and to recognise the importance of their symptoms."

Dr Ian McPherson, Director, National Institute for Mental Health in England (NIMHE), West Midlands

"People with SMI often feel trivialised by primary care when they present with a health issue that concerns them. They feel once they are given their diagnosis they are seen in terms of that diagnosis and nothing else. It is important that people with SMI are listened to and that their concerns are taken seriously by health care professionals to ensure they are then more motivated to care for their own well-being."

Michelle Rowett, Chief Executive, MDF The BiPolar Organisation

However, due to a number of factors such as distrust of healthcare professionals because of past experiences, instances do exist where individuals may also be less co-operative than a member of the general population, which will likely act as a barrier between themselves and their healthcare professional team.[21] 'Diagnostic overshadowing' could also

contribute to the problem, where physical symptoms are seen in terms of the mental health problem and may be perceived as 'all in the mind.'[22] These are invariably costly misperceptions which often result in the neglect of real physical conditions and contribute to further disengagement from care.

"Provision of care throughout mental health services is still far too patchy with skills and competencies being extraordinarily variable. In addition, some mental health professionals and staff are themselves disillusioned, or burning out, and this further affects their capacity to deliver those skills and competencies that they do have."
Dr Chris Manning, Chief Executive, Primary Care Mental Health Education (PriMHE)

The increased mortality amongst people living with SMI has been attributed, at least in part, to the substandard medical care that they receive.[23] Recent reforms in mental health care have led to the closure of long-stay mental hospitals and the development of community mental heath teams (CMHTs) which are now expected to meet the whole range of health and social needs.[24] Hospital admissions in SMI are often short and infrequent and physical healthcare and lifestyle management are not necessarily given priority.[25] In addition, many mental health care practitioners have little training in how to manage physical care, the rates of physical assessments of those under care in hospital by junior psychiatrists are poor[25] and the monitoring of physical health and health education by CMHT staff is generally unsatisfactory.[26] In addition, healthcare services are often fragmented and un-coordinated, with both clinicians and those under care, unaware of available and appropriate resources.[25,26]

"There are not enough resources or time to implement guidelines and health promotion around physical health care in those with SMI. People see it as a trimming rather than a basic necessity of care."
John Pendlebury, Community Psychiatric Nurse, Salford

The majority of GPs believe that it is their responsibility to handle physical health matters and lifestyle management and it is indeed a key quality indicator in their contract. However, it is clear there is not enough time or money for this in the primary care provision of mental health care. As such, for those with SMI who are in contact with a GP, this does not necessarily ensure that they receive good health care either. The orientation of primary care is reactive, and this does not fit well with those who may be reluctant, or unable to seek help.[24] Short consultation times make it difficult for doctors to assess mental state, conduct a physical assessment and provide lifestyle advice, especially in those individuals who are unsure, unconfident or confused.[24]
An added limitation is that up to a third of individuals with SMI may move out of their locality within a year and peripatetic lifestyles can make it difficult for services to stay in touch.[16]

"Services exist for those who use them, not those who provide them. We need to join up our thinking and working, from Government Departments right down to the 'sharp end' and be centred in the reality of the needs, wishes and predicaments of those affected by SMI, their families and cares. Real teamwork leads to greatly improved outcomes for those receiving care and the morale and wellbeing of the professionals in those teams."
Dr Chris Manning, Chief Executive, Primary Care Mental Health Education (PriMHE)

"Despite what many health care professionals think, people with SMI are concerned about their physical health. We should therefore be providing them with effective and appropriate health services, looking at well-being across the board."
Elizabeth Gale, Director, mentality

"Better coordination between primary care, psychiatrists and endocrinologists is required in order to implement well-being effectively in practice. Further education is also required for doctors, people affected by SMI, their families and carers alike on the importance of a holistic approach to care."
Dr Jogin Thakore, Consultant Psychiatrist, St. Vincent's Hospital, Fairview, Dublin

Section 1: The Scale of the Problem

"It is easy to blame the person experiencing symptoms for a lack of self-care, however it is important to recognise that when people do present with physical problems, health services are too ready to ignore symptoms and attribute them to mental health problems rather than carrying out proper investigations and identifying the causes."
Dr Ian McPherson, Director, National Institute for Mental Health in England (NIMHE), West Midlands

Living Conditions

"People on low incomes who are without work or homeless are all indicators for poor health outcomes regardless of mental health."
Michelle Rowett, Chief Executive, MDF The BiPolar Organisation

According to the Social Exclusion Unit, in 1998 there were still 2,000 roofless people in England each night; 10,000 over a year.[15] Of these, between 30 and 50 per cent experienced mental health problems.[15] A report Pressure Points (1999) by the national homelessness charity Crisis estimated that; 33 per cent of those who are evicted from accommodation, 60 per cent of homeless people and 20 per cent of roofless people, have SMI and people who sleep rough are 35 times more likely to kill themselves than the general population.[15] In combination with the fact that accessing healthcare without a permanent address has its own issues, it is therefore understandable that caring for ones overall general health is not a priority for these individuals living with SMI.

"The approach to physical health checks and lifestyle management needs to be more assertive. Individuals with SMI are unlikely to volunteer for schemes unless proactively approached."
Professor Kevin Gournay CBE, Head of Psychiatric Nursing, Institute of Psychiatry, London

Conclusions

To conclude section one, *Running on Empty* report authors would like to highlight the following:

In addition to living with mental health problems, those with SMI are also significantly more at risk than the general population of developing major physical health-related issues such as cancer, cardiovascular disease, type 2 diabetes, obesity and HIV/AIDS.[3,4,7] This increased incidence translates into rates of premature death which are up to three times higher than the general population.[3] In order to address these well-being issues, a holistic, supportive, choice-driven approach must be widely adopted into the everyday provision of care and delivered by all healthcare professionals.

"The physical well-being of those affected by SMI matters more than we, as professionals, sometimes realise. We must take notice of it."
Annette Jones, Nurse Advisor, St David's Community Mental Health Trust, Aberdare

"We need to mainstream mental health and make sure it is on everybody's agenda, not just seen as a sideline to other illnesses."
Dr Ian McPherson, Director, National Institute for Mental Health in England (NIMHE), West Midlands

Section 2: The Current Management of Well-Being in Severe Mental Illness

> *"No matter how much guidance may help us, those affected by long term-mental illness should be treated as individuals in terms of their overall care."*
> ***Professor Robert Peveler, Professor of Liaison Psychiatry, University of Southampton***

What Guides Healthcare Professionals' Management of SMI?

In recent years, the management of mental illness has received considerable attention and has been the focus of much guidance and healthcare policy. Several major initiatives have been introduced with the aim of improving the management of mental illness in England and Wales.

Most notably, these include the National Service Framework (NSF) for Mental Health for England[16] and Wales,[27] the National Institute for Clinical Excellence (NICE) Clinical Guideline 1[28] on schizophrenia and the inclusion of quality points for mental health care in the GMS Contract.[29] Furthermore, legislation on disability discrimination and mental health, recommendations from professional bodies and advocacy groups and NHS reports also have an influence on the way mental illness is treated in the UK.[7,30,31]

Recommendations relating to a holistic approach to care in people with mental illness are included in much of the guidance. In particular, NICE is the most useful and comprehensive in terms of the development of SMI Registers. However, while these initiatives are valuable, there is still a lack of clarity about who should be in charge of the mental and physical aspects of care for people with SMI.

For healthcare professionals faced with over 200 pages of official guidance relating to the management of mental illness, it can be difficult to determine the important areas on which to focus. To investigate this further, for the purpose of the *Running on Empty* report, a total of 209 GPs from across the UK were surveyed during March 2005 by the independent market research agency TNS Healthcare for their opinion.[5] Survey data reveal (further data from this survey is outlined on page 16) that only half of GP's provide lifestyle advice on healthy eating, weight management or exercise.

A parallel survey, again conducted specifically for the report, revealed 48 per cent of those under care claim never to have been referred to a lifestyle management programme and less than 10 per cent of those living with SMI currently participate in lifestyle management schemes.[6] In addition, in a survey amongst individuals with SMI and their carers, 86 per cent of those asked said they had not received the record taken of their health history.[6] This market research was also conducted by the independent market research agency TNS Healthcare. During February and March 2005, 325 individuals obtaining scripts for schizophrenia or bipolar disorder completed questionnaires in TNS Healthcare's Spotlight panel of 400 community pharmacies across the UK. Further data from this survey is outlined on page 17.

The results from the two surveys indicate that a clear and structured approach therefore is required for the successful implementation of these recommendations in order to achieve meaningful improvements in the overall well-being of people with SMI. It is also possible that those documents guiding clinical practice require further clarification and distillation which this section aims to achieve.

The National Service Framework for Mental Health for England (September 1999) and Wales (April 2002)

The publication of the NSF for Mental Health for England[16] and Wales[27] marked the Government's intention to raise the priority of mental illness within the NHS. The need to address well-being is emphasised in both by the inclusion of recommendations relating to the assessment and maintenance of physical health in the care of individuals with mental illness.

Key points

- Physical health should be reviewed regularly (at least on an annual basis)
- Arrangements for physical healthcare should be included in the written care plans for individuals on an enhanced care programme approach (CPA), including details of how and what physical healthcare will be provided
- The important role that primary care can play in caring for the physical health of people with mental illness is emphasised. It is suggested that the primary care team should usually take responsibility for physical healthcare, but that they may take on a more extended role in agreement with the care co-ordinator
- Standards two and three of the NSF require primary care to work in conjunction with specialist mental health services who have the skills and the necessary organisational systems to provide the physical healthcare and other primary care support needed as agreed in their care plan for people with SMI

Section 2: The Current Management of Well-Being in Severe Mental Illness

NICE Clinical Guideline 1: Core interventions in the treatment and management of schizophrenia in primary and secondary care (December 2002)

The purpose of the clinical guideline published by NICE[28] is to help improve the experience and outcomes of care for people with schizophrenia. At present, NICE guidance relating to bipolar disorder is in development, therefore those with the condition are currently at risk from varying standards of treatment. Highlights from the guidance include:

Key Points

- It is the responsibility of GPs and other primary health workers to regularly monitor the physical health of people with schizophrenia registered with their practice – the frequency of checks will be a clinical decision made jointly between the service user and clinician and recorded in the case notes
- Secondary care services should undertake regular and full assessment of the mental and physical health of their service users with all the issues relevant to a person's quality of life and well-being being addressed
- Physical health checks should pay particular attention to endocrine disorders, such as diabetes and hyperprolactinaemia, cardiovascular risk factors, such as blood pressure and lipids, side effects of medication, and lifestyle factors such as smoking – details to be recorded in the case notes
- Assessment of health and social care needs for people with schizophrenia should be comprehensive and address physical, as well as medical, social, psychological, occupational, economic and cultural issues
- The higher physical morbidity and mortality of service users with schizophrenia should be considered in all assessments
- The organisation and development of practice case registers for people with schizophrenia is recommended as an essential step in monitoring the physical and mental health of people with schizophrenia in primary care
- When a service user chooses not to receive physical care from his or her GP, this should be monitored by doctors in secondary care
- Primary and secondary care services, in conjunction with the service user, should jointly identify which service will take responsibility for assessing and monitoring the physical health care needs of service users. This should be documented in both primary and secondary care notes/care plans and clearly recorded by care co-coordinator for those on the enhanced CPA

The General Medical Services (GMS) Contract (April 2004)

Similarly to the NICE guidance, the GMS contract[29] clearly states that the provision of physical health care for people with SMI is the responsibility of primary care and underlines the need for members of the primary health care team to communicate effectively with the CMHT.

Under the GMS contract, GPs are encouraged to be more proactive in addressing the physical health needs of adults with SMI. A practice register of all people with a diagnosis of schizophrenia or bipolar disorder should be set up to enable targeted care to be offered to this group. This provides a useful framework on which to build closer relationships between primary health care teams and the CMHT attached to the practice to ensure that those under care are not missing out on the care they need.

> *"The new GMS contract has given GPs a clear message that it is the responsibility of primary care to offer a package of holistic care to people with severe mental illness. Often the GP does not see their role as providing lifestyle advice, therefore a huge culture change is required to ensure these services are provided."*
> ***Professor Kevin Gournay CBE, Head of Psychiatric Nursing, Institute of Psychiatry, London***

Unlike the other GMS-guided registers – such as those for people with diabetes, the GMS contract for mental health states that specific permission must be sought from individuals with SMI for inclusion in a practice's SMI register. This a fundamental flaw in the process as those affected by SMI are often reluctant to be recorded on a register due to the perceived stigma attached. However, because each individual must be identified in order to be initially approached, this at least allows the register holder to identify those requiring care for SMI. In the past this has been extremely problematic.

"The GMS contract encourages GPs to set up practice registers, however reluctant individuals have the option not to be enlisted, which inevitably leads to many of those living with long-term mental illness are falling through the net of care."
Professor Robert Peveler, Professor of Liaison Psychiatry, University of Southampton

"Many of those affected with SMI feel there is stigma attached to practice registers and by signing one they will then live with this permanent record or label. We need to educate individuals on the benefits of joining registers, which are important in order to monitor the long-term management of their chronic illness."
Professor Andre Tylee, Professor of Primary Care Mental Health, Institute of Psychiatry

"People with SMI are often treated differently once they are given a mental health label, which is part of the problem in trying to persuade individuals to sign the register. A cultural change is needed in the way health care professionals communicate with those affected by SMI."
Dr David Yeomans, Consultant Psychiatrist, University of Leeds

Practices are also awarded points for the percentage of individuals who have been reviewed within the last 15 months. This review includes a check on the accuracy of prescribed medication, a review of physical health and a review of co-ordination arrangements with secondary care.

There are, however, concerns about the GMS contract as a whole due to only 41 out of a possible 1000 points being related to mental health. When compared to points awarded for diabetes and cardiovascular disease, monitoring the well-being of those with SMI does not stand out as a priority and may not provide enough of an incentive for primary care.

However, because of the medical co-morbidity of SMI, it is likely that those with SMI will also appear on other registers (such as those for diabetes and coronary heart disease). It is also worth noting that in comparison to developing a register for cardiovascular disease which may include hundreds of individuals and take significant time to set-up, an SMI register may be relatively easy to initiate. This is based on the consideration that a GP with an average register of about 1600 will only have five to six people with a psychotic illness (SCMH).

"SMI should be managed in the same manner as any other chronic illness. At present, mental health is not a priority in comparison to other disease areas and the points awarded for these. In the future an integrated approach should be implemented where points for diabetes and CVD may only be awarded if these same aspects of care are administered in those with SMI."
Professor Andre Tylee, Professor of Primary Care Mental Health, Institute of Psychiatry

Quality Indicators – Summary of Points for Mental Health

All minimum thresholds are 25 per cent

Indicator	Points	Maximum Threshold
Records		
MH 1. The practice can produce a register of people with severe long term-mental health problems who require and have agreed to regular follow-up	7	–
Ongoing Management		
MH 2. The percentage of patients with severe long-term mental health problems with a review recorded in the preceding 15 months. This review includes a check on the accuracy of prescribed medication, a review of physical health and a review of co-ordination arrangements with secondary care	23	90%
MH 3. The percentage of patients on lithium therapy with a record of lithium levels checked within the previous 6 months	3	90%

Section 2: The Current Management of Well-Being in Severe Mental Illness

Indicator	Points	Maximum Threshold
Ongoing Management *(Continued)*		
MH 4. The percentage of patients on lithium therapy with a record of serum creatinine and TSH in the preceding 15 months	3	90%
MH 5. The percentage of patients on lithium therapy with a record of lithium levels in the therapeutic range within the previous 6 months	5	70%

Other Initiatives

In addition to main guidance, there are several other bodies which influence the treatment of SMI. The Disability Discrimination Act (1995) makes it unlawful for service providers to treat disabled people less favourably than others and requires service providers to make reasonable adjustments where necessary for disabled people to use services.[8]

"The social inclusion agenda is important. People living with SMI have as much right to see a GP. Often they are labelled as a person with a severe enduring mental illness and the present concerns surrounding their condition are dealt with, neglecting other range of needs."
Professor Andre Tylee, Professor of Primary Care Mental Health, Institute of Psychiatry

Mental Health Legislation supports measures to address the physical health needs of mental health service users. In particular, the Mental Health Act entitles people who have been detained, to a comprehensive after-care package following discharge from hospital.[32]

The NHS has also published several plans and reports over the past few years regarding the development of services that impact on the physical health care of people with SMI. Their most recent is the NHS Improvement Plan[30] which sets out priorities for the NHS until 2008, supporting initiatives that improve the physical health of people with SMI. One of these initiatives is the Expert Patient Programme, which will be rolled out nationally and is designed to empower those affected by illness to manage their own healthcare.[30] The programme will enable people with SMI to listen to themselves and their own symptoms, supported by their clinical team.

January 2005, Supporting People with Long Term Conditions: NHS and social care model to support local innovation and integration, was published by the Department of Health to improve the support for people with long-term conditions such as mental health problems.[31] It identified that wholesale changes are required to the way health and social care services are delivered and argues that care for many people with long term conditions has traditionally been reactive, unplanned and episodic.

The Supporting People with Long Term Conditions NSF published in March, 2005, builds on the NHS and Social Care Model by exploring how person-centred care planning, information and support, self care, disease management and case management can be put into practice to transform services for people living with long-term conditions.[33]

It also notes that the Public Health White Paper Choosing Health[34] underpins the entire long-term condition approach and also enforces the importance of improving well-being through lifestyle management. This will build on the public's growing desire for a healthier future by ensuring that self care support is in place for people – particularly those in disadvantaged groups and areas – to make healthier choices about diet, physical activity and lifestyle.

Current Management of SMI: Is Enough Being Done?

It is clear from various government initiatives that it is not just the care of mental health in those with SMI that is acknowledged, but increasingly the physical health care and lifestyle management of individuals as well. There is relatively little information on how successfully HCPs implement recommendations in practice. However, further results from the survey of UK GPs conducted for this report (page 13), reveal nearly four in every five GPs have systems in place to ensure that those with SMI receive annual health checks.[5]

Despite this encouraging figure, there does appear to be gaps in the provision of lifestyle advice to people with SMI:

- More than one in every five GPs say they did not offer lifestyle advice to those in their care with SMI
- Only around half of GPs provide advice on health eating, weight management or exercise
- Fewer than one-third of GPs refer those with SMI to support programmes

"At present there is a lack of time and resources to help those in primary care manage the overall heath of those with SMI."
Professor Andre Tylee, Professor of Primary Care Mental Health, Institute of Psychiatry

In addition, liaison with other services to ensure that those with SMI received care for their physical health has been illustrated as suboptimal. More than half of the GPs taking part in the study admit that no one in their practice liaised on a regular basis with other health care professionals (e.g. psychiatrists, diabetologists, nutritionists) to ensure those with SMI under their care receive appropriate general health care. This demonstrates the greater need for collaboration amongst HCPs to formulate a holistic care plan.

Further results show nearly ten per cent of GPs would discuss a change in medication with the prescriber first for individuals presenting with a lifestyle issue such as weight gain. A similar number were unsure about what action they would take, however, the vast majority (84 per cent) revealed they would address lifestyle factors first; reflecting what is generally thought to be best practice. This demonstrates that HCPs recognise the importance of discussing the choices available with those in their care.

In the survey amongst those with SMI and their carers – again referred to earlier in the report (page 13) – the questionnaire delved deeper into the provision of health care received and results reveal that 72 per cent of respondents claim to have received a general health check within the last year, again an encouraging figure, however, on closer observation of results:

- 86 per cent did not claim to have a record taken of their health history
- 78 per cent did not cite having been offered a blood sugar test
- 71 per cent did not mention being provided with lifestyle management advice
- 69 per cent did not state being offered weight management advice
- 49 per cent did not recall being offered a blood pressure test

These results demonstrate that the physical health checks undertaken and lifestyle management advice offered is by no means ideal. Whilst it is important to acknowledge the majority receive some sort of general health check annually – as recommended by guidelines – it needs to be ensured that all individuals with SMI are offered the entire range of health checks and lifestyle advice required.

"Lifestyle management is not widely adopted by healthcare professionals because of lack of awareness and resources needed to simultaneously address both physical and mental health. Current systems are non-holistic."
John Abbott, Public Affairs Manager, Hafal

"A well-being approach is not being implemented more widely in practice as it is a challenge to make people with SMI to comply with their medication and to change their lifestyle they adopt. In addition, there is little funding for such activities and many health care professionals may think that people with SMI are not concerned about their health, which is probably not true."
Stephen Gough, Professor of Medicine, University of Birmingham

In the same survey, 62 per cent of respondents said they had never participated in a lifestyle management programme due to either lack of interest or awareness. GPs were recognised by the majority of those completing the questionnaire as their main point of contact followed by practice nurses and CPN/CMHNs. This supports guidelines which recommend primary care as the main carer for those affected by SMI, however acknowledges the fact that they must also be supported by other HCPs too.

These survey results illustrate that despite government directives acknowledging lifestyle factors as important contributors to poor health, management is often overlooked, varies in the schemes made available and is under prioritised by HCPs. The current situation can be attributed to a number of challenges such as a reluctance of individuals with SMI to visit their GPs, a lack of resources, a lack of clarity in guidelines and shortcomings in guidance. HCPs are increasingly aware and in agreement of what these challenges are and in light of this, greater steps should be made to ensure a more united approach is taken, where HCPs support one another and provide a level of care that those living with SMI are entitled to.

Section 2: The Current Management of Well-Being in Severe Mental Illness

Conclusions

To conclude section two, *Running on Empty* report authors would like to highlight the following:

Recent survey results illustrate that despite government directives this provision of care to address the entire well-being of those with SMI is often lacking and overlooked. Whilst the current situation can be attributed to a number of challenges, greater steps should be made to ensure a more united approach is taken, where healthcare professionals support one another and provide a level of care that those under care are entitled to receive.

> *"The lack of physical health care for people with chronic mental illness is a very neglected problem. Clinicians and other healthcare professionals tend to think in boxes and compartmentalize care, with the result that physical health issues are often left neglected."*
> ***Robert Peveler, Professor of Liaison Psychiatry, University of Southampton***

Section 3: Improving Well-Being in People with Severe Mental Illness

What Is Already Being Done?

Although initiatives such as the English and Welsh National Service Frameworks for Mental Health, NICE-led documentation and the GMS contract include specific actions on physical health and lifestyle management, it is widely thought that the targets and aspirations set out remain unmet.

> *"We can no longer have the mind / body separation that historically existed in people's training. It is important for health care professionals to understand how mental health can affect overall physical health and vice versa. We need to challenge the current approach and require a major culture change in how we care for those affected by SMI."*
>
> ***Dr Ian McPherson, Director, National Institute for Mental Health in England (NIMHE), West Midlands***

Policies and projects are needed to implement the recommendations. There are a growing number of initiatives around the country that have been developed by the Disability Rights Commission, Hafal, **mentality**, NIMHE and Rethink to increase awareness of the need to improve the general well-being of people with SMI.[8,35,36] However, there are – as yet – no universally available programmes to address this issue.

> *"In the future there needs to be better integration between primary and secondary care, including more combined nurse led clinics and a more proactive approach taken by GPs and psychiatrists to achieve greater awareness of the problem."*
>
> ***Professor Stephen Gough, Professor of Medicine, University of Birmingham***

Outcomes of well-being schemes that have been implemented in practice are included within this report to exemplify the real life benefits of programmes and what can be achieved when all HCPs work together in each of their designated roles, combining effective medication with lifestyle management and regular health checks.

Well-Being in Practice

A survey conducted by Rethink demonstrated the benefits of measures taken to improve the physical activity of those living with SMI, with 85 per cent finding schemes to be of therapeutic value.[8] NIMHE suggests that efforts to improve physical activity are relatively simple, could benefit a range of physical health outcomes, need not be expensive and should be advocated for all.[8] Promoting physical activity can benefit people with SMI in a number of ways including weight control, improved mood and increased self esteem. Similar advantages have been observed in a variety of well-being programmes tackling different lifestyle issues, exemplifying not just the physical but social benefits of such initiatives.[37,38,39]

These schemes implemented in conjunction with the necessary general health checks, will help ensure the overall care of those with SMI is looked after and ultimately improve overall treatment outcomes. There are a range of well-being management schemes that have been set up by a variety of different organisations, which have demonstrated that they can successfully improve the physical health of people with SMI. Examples of best practice are included below:

Well-Being Support Programme

The Well-Being Support Programme was launched in March 2003, recognising the need to initiate a holistic and integrated care system for those with SMI. The ongoing programme, sponsored by Lilly, began with eight nurses and eight sites (seven in England and one in Wales) and was expanded in January 2005 to 13 nurses and sites. Further expansion is planned for 2005 and beyond.

Completely aligned to government-set policy and guidance, the Well-Being Support Programme has been specifically developed to:

- Improve the overall general health of individuals affected by SMI
- Support the NHS in the achievement of mental health targets around physical well-being
- Develop a committed partnership with the NHS to improve outcomes for those with SMI

The Well-Being Support Programme offers a training scheme for NHS nurses which includes provision of all materials and tools needed to deliver the Well-Being Support Programme service, along with a comprehensive mentorship scheme and support package following completion of training.

Section 3: Improving Well-Being in People with Severe Mental Illness

On completion of training, NHS nurses will then be able to offer assessments and advice for those with SMI enrolled in the Programme on the following:

- General Health (including blood pressure, pulse rate, blood glucose and lipid and cholesterol levels)
- Lifestyle (including smoking, diet, physical activity levels, illicit substance and alcohol use)
- Side Effect Management
- Interventions

Benefits of the initiative have already been acknowledged by HCPs and over 1,000 individuals with SMI who have benefited from the Programme.[34] In addition, the recent government white paper 'Choosing Health' has recognised that the NHS can learn from the successful implementation of the Well-Being Support Programme.

Experience from the Programme has demonstrated that intervention and support offered by nursing staff on small dietary changes can work in motivated individuals; this is evident through the loss of weight from clients. Attendees have been willing to attend weekly clinics and have shown that they feel valued because someone is taking an interest in their lifestyle. The Programme also provides friendship and support networks.

> *"The Well-Being Support Programme has had a significant impact on the lives of those involved. In particular, we have been able to identify the onset of disease in those with SMI before complications arise. This shows the real life benefits of such schemes."*
> ***Dr David Yeomans, Consultant Psychiatrist, University of Leeds***

Projects in the NHS: Lewisham Primary Care Trust Project

This project was piloted in 2002 and is sponsored by Lewisham Primary Care Trust.[8] The aim was to help GPs work more closely with Community Mental health Teams to improve the physical health of clients with severe and enduring mental illness on an enhanced Care Programme Approach (CPA). Each client on enhanced CPA is offered an annual check. Their care co-coordinator helps them make an appointment at their general practice with the practice nurse and the check takes about half an hour, consisting of height and weight measurement, blood pressure and urine testing, discussion about previous illness and an opportunity to raise any physical health concerns such as problems about eyes, feet or teeth.

Outcomes are sent to the community mental health team so they can promote concordance with follow up tests or treatment. At all stages the client is asked for their permission before information is shared with other health professionals. If physical health problems are identified, the practice treats them in the same way as all other members, following standard protocols for example for blood pressure checks or diabetes, asthma or coronary heart disease management.

In the Lewisham pilot project, an ex-community psychiatric nurse and a practice nurse were given training in providing physical health checks for those with SMI. They then ran training at Community Mental Health Team premises for practice nurses in Lewisham PCT, providing an opportunity for community mental health workers and practice nurses to learn about each other's role. The training addressed issues around stigma and discrimination, helped provide practice nurses with the skills to implement health checks and allowed nurses to see themselves as the right person to do these checks.

'At the start of the work in Lewisham we were concerned that clients would not want to attend, but so far the majority of people have. An unmet need for physical health checks has been revealed and people have been helped to access other services such as community dentistry, chiropody and smoking cessation advice.' (Clinical Governance Facilitator, Health Body and Mind – NIMHE 2004)

Weight Management Clinics

Weight management groups have been shown to be an effective tool for supporting healthy eating as well as developing other skills such as nutrition awareness, shopping and cooking for these often isolated individuals.[8,39] One team at the Mental Health Services of Salford, set up a weight management clinic staffed by a community psychiatric nurse and an occupational therapist where people with SMI self refer to the clinic.[39]

> *"All people living with SMI should be made aware of the increased risk of poor general health associated with their condition so that they can then seek information on the steps they can take to reduce the risk."*
> ***John Pendlebury, Community Psychiatric Nurse, Salford***

The weight management programme educated participants about weight management and comprised of an 8-week rotational topic cycle. Sessions were conducted in weekly groups lasting one hour. The sessions were divided into initial weighing, followed by a discussion within the group, where experiences from the previous week were shared. Eight topics were addressed in rotation: healthy eating, exercise, self-esteem, meal planning and demonstrations, activity scheduling, motivation, quizzes and evaluation. Additional sessions were incorporated to help participants address potential weight issues around Christmas, Easter, birthdays and school holidays. Basic self-monitoring skills were also taught to those participating.

Information on age, sex, GP, height, blood pressure, medication and weight at each session, were recorded for each person attending. Results at 36 months, for 70 participants were encouraging, revealing that they managed to achieve a mean weight loss of 4.7 kg (SD 5.5) at a mean rate of -0.25 kg per session (SD 0.3) [the mean BMI for those attending was 32.5kg/m^2 (SD 5.1).[39] Weight loss was highly correlated with number of sessions attended (p=0.0001) and appeared to be independent of BMI or medication.[39]

The team considered that their findings indicated a significant long-term benefit of a weight management programme and supported the hypothesis that weight gain is manageable with simple interventions in motivated people. Further findings showed that the programme had reduced concerns amongst both clinicians and those in their care about weight gain and reduced the need to change medication

"We have seen significant benefits in those with SMI attending weight management clinics. It is as much a regular social activity as a weight management clinic and consequently we have seen self confidence of participants increase as they begin to socialise more with others and begin to feel good about themselves again."
John Pendlebury, Community Psychiatric Nurse, Salford

Learnings from Well-Being in Practice

It is possible to improve the physical health of this vulnerable section of the population. Progress will, however, depend on both mental health and primary care staff being aware of the problem and being willing to find imaginative solutions which are acceptable and useful to those being cared for.

The concept of well-being – which involves effective lifestyle management and regular physical health checks together with effective medication for the treatment of individuals with SMI – has only been acknowledged by guidelines and implemented in practice over the last few years, yet already we are seeing the benefits of such schemes.

Best practice examples show that an integrated approach, involving all HCPs can indeed be achieved with improved treatment outcomes for those with SMI. The key learnings we can take away from these schemes, which is also acknowledged in recent survey data,[5,6] are that primary care should act as the main source of contact for those affected by SMI.

"The physical health of those with SMI should be initiated in primary care and monitored by community mental health teams."
Professor Kevin Gournay CBE, Head of Psychiatric Nursing, Institute of Psychiatry, London

It is essential to 'embed' into local health and social care communities an effective, systematic approach to the care and management of individuals with SMI. To achieve this measures are needed to reduce the reliance on secondary care services and increase the provision of care in a primary, community or home environment. GPs should work with their primary health care team to share responsibility of care and create active links with community mental health services to ensure effective treatment of physical health care is managed among those with SMI. Every individual with SMI should be offered annual health checks which can be carried out by a practice nurse to screen for disease and the practitioner overseeing physical health care can liaise with other agencies such as specialist lifestyle management clinics to make direct referrals if necessary.

"Nurses are the greatest source of the care force to drive well-being initiatives because they have more time to spend with those in our care, to provide advice and to follow-up with them, which is essential for management of a chronic disease such as severe mental illness."
Professor Kevin Gournay CBE, Head of Psychiatric Nursing, Institute of Psychiatry, London

Section 3: Improving Well-Being in People with Severe Mental Illness

The importance of routine physical care has been acknowledged, but needs to be implemented more consistently. It should include, measurement of blood pressure and weight, regular dental and optical appointments, detection of diabetes and cancer, e.g. cervical smears for women, monitoring chest and heart and detecting and monitoring side-effects of medication. Primary care should also offer follow-up care and advice within the practice for most areas including diabetes, hypertension, asthma, and health promotion, which can be monitored by the practice nurse. As a result, those affected with SMI will become more used to attending the surgery and will be more likely to access the facilities provided.[8]

> *"People living with SMI are impacted by a demarcation of service. We acknowledge that nurses need to take more responsibility for care as part of a team that operates correctly within well-understood parameters."*
> ***Ian Hulatt, Mental Health Adviser, Royal College of Nursing***

In addition, doctors should recognise any possible signs of relapse first to ensure that the medication is working effectively. Subsequently they should look for potential side-effects of treatment as early as possible, ensuring that they are monitored and managed, and individuals with SMI in their care should be referred to lifestyle management schemes. HCPs should discuss the possibility of weight gain when someone starts taking medication and monitor any change in weight, providing preventative advice from the start of treatment. If weight gain is a problem, they should offer dietary advice or refer people to a dietician or weight management group.

> *"Proper collaboration between primary, secondary and other care is required, minimising duplication where each professional contribute to the complete care of those with SMI."*
> ***Professor Andre Tylee, Professor of Primary Care Mental Health, Institute of Psychiatry***

In hospital, those with SMI should have opportunities for exercise, good quality, nourishing meals and ready access to drinks (and snacks) at all times, recognising that some medication causes dryness of the mouth. In the community, mental health services should check that these individuals receive adequate meals, and arrange help with this where necessary, including recommending a suitable diet.

Overall, general health staff must have the knowledge, skills and motivation to treat and manage people living with mental disorders. Effective referral links between primary, secondary and tertiary levels of care need to be in place to ensure those with SMI do not fall between the cracks and recording systems need to be set up to allow for continuous monitoring, evaluation and updating of integrated activities.

> *"Helping people to achieve their optimal levels of well-being and quality of life is an excellent approach to care because it is based on what people can achieve rather than on endless medical-only conversations about history, putative attribution of illness causation and thwarted life ambitions. A well-being, recovery approach is capacity-based and building, and puts those with SMI, their families and carers, in far more every day control of their lives. It values their contribution in a genuine way, rather than consisting of merely polite tokenistic nods in their direction. At the same time, all those involved in delivering holistic solutions and their patients can be reminded that recovery is about progress, not perfection."*
> ***Dr Chris Manning, Chief Executive, Primary Care Mental Health Education (PriMHE)***

Long term conditions such as SMI require high-quality care, personalised to meet individual requirements. Another critical aspect of this well-being approach therefore is the fact that those with SMI are placed back in control of managing their own care and are acknowledged as having a central role which often empowers them, their family and carers to handle their condition as effectively as possible.

> *"Responsibility for access to health services falls on both the shoulders of the person with SMI and the health care professional Team."*
> ***Dr Richard Holt, Senior Lecturer in Endocrinology and Metabolism, University of Southampton***

Conclusions

To conclude section three, *Running on Empty* report authors would like to highlight the following:

A number of programmes, initiatives and schemes are available that allow those affected by SMI to proactively manage their own care. However, these are under-prioritised by the healthcare professional team. There are several examples of best practice where schemes tackling lifestyle issues have been shown to improve overall well-being outcomes for those with SMI. Programmes need to be kept as simple and as flexible as possible in order to enable individuals to progress at their own rate and incorporate advice into their own lifestyle.

> *"It is vital that those living with serious mental illness should be able to rely on their health being looked at in the round, with physical health needs given as much attention as mental health needs. We know from our callers how much they value consistent care from the same professionals, and how few get this. The joined-up thinking proposed in this report would make so much difference to people in managing their illness, and confidence to families and carers that problems are not going unnoticed."*
> ***Marjorie Wallace MBE, Chief Executive, SANE***

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