



twice as likely:
putting long term conditions
and depression on the agenda

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executive **summary**



Long term conditions coupled with depression are a significant and growing challenge for health and social care services. Between 15.4 to 17 million people have long term conditions. **People with long term conditions are twice to three times more likely to experience depression** and estimates suggest that 20% of people with long term conditions have depression.

*There are two main types of diabetes. Type 1 develops when the body's immune system destroys the cells that produce insulin and the body is unable to produce any insulin leading to increased blood glucose levels. It usually appears before the age of 40, and especially in childhood. Type 2 diabetes develops when the body can still make some insulin, but not enough, or when the insulin that is produced does not work properly. Type 2 diabetes usually appears in people over the age of 40, though in South Asian and black people, who are at greater risk, it often appears from the age of 25.

Depression can affect people with a range of long term conditions:

Musculoskeletal conditions (these are conditions of the joints, bones and muscles – including back pain, rheumatoid arthritis and osteoarthritis - along with less common but serious systemic autoimmune diseases such as lupus)	The most common form of arthritis is osteoarthritis, which is the leading cause of pain and disability in this country, affecting 8 million people. Depression is common here, with 68% of people with arthritis reporting depression when their pain was at its worst. ^{1a} Over 10% of people with rheumatoid arthritis report symptoms of depression.
Cancer	49% of people with cancer say they experience depression as a result of their diagnosis.
Diabetes*	41% of people with diabetes have depression. It is at least twice as common in people with diabetes as the general population and between 30-50 per cent of cases are undetected.
Heart disease	Depression is two or three times more common in a range of cardiovascular diseases.
Other conditions	Up to 40% of people with alzheimer's disease have depression. It is twice as common in people with HIV/AIDS and it is also common in people with hepatitis C, muscular dystrophy, respiratory disease and stroke.

The prognosis for people with long term conditions and depression is poorer care, poorer outcomes, a poorer quality of life and a substantial cost to the NHS; £8 to 13 billion is said to be the cost of care for those with long term conditions and mental health conditions in England¹, with depression being the most common mental health problem. Studies indicate that depression can increase healthcare costs by 33% to 169% over a range of long term conditions.¹

Importantly also, depression can increase the risk of death for people with some long term conditions such as heart disease and cancer. A study has suggested a possible association between depression and cancer deaths. Additionally, it is estimated that the UK economy stands to lose £16 billion over the next 10 years through premature deaths due to heart disease, stroke and diabetes.

Furthermore, our ageing population makes the challenge of depression and long term conditions even more pressing. Older people are more likely to have a long term condition and the numbers of older people is growing. By 2035, 23% of the population will be over 65 including 5% aged over 85.

The Quality, Innovation, Productivity and Prevention agenda clearly calls on health services to make efficiency savings of £20 billion by 2014-16 in the NHS by providing more innovative, joined-up and high quality care. Improving care for long term conditions and depression provides an opportunity to make savings in the NHS. Depression in those with long term conditions can exacerbate illnesses, lessen adherence to medication and inhibit rehabilitation and recovery, increasing the costs to the NHS through more unplanned hospitalisations and additional GP consultations.

We also welcome the opportunities to improve care and services for people with long term conditions and depression presented in the Long Term Conditions Outcomes strategy, which the Department of Health is due to publish by the end of 2012.

Our vision and recommendations

When a person is diagnosed with a long term condition, it can be devastating news. When a person is unable to carry out their everyday activities or have to change their lifestyle due to a long term condition, it can have a devastating impact. Services for people with long term conditions must take into account the emotional and psychological impact of being diagnosed or living with a long term condition.

We would like every person with a long term condition to be treated for both their physical and psychological symptoms in equal measure, recognising the detrimental impact depression can have on the health outcomes and quality of life.

It is essential that the implementation of any strategy to involve people with long term conditions in the planning of their care, especially around emotional and psychological issues, does not become a 'tick box exercise' for either the NHS or front line staff. Simply having a Plan of Care, although helpful, will not achieve the outcomes required for people with long term conditions. This is a complex issue and therefore requires a comprehensive approach.

Our **vision** is for:

Every person with a long term condition to be enabled to engage in agreeing a 'Plan of Care' in conjunction with a health and/or social care professional through a planning process which assesses their physical and psychological needs equally.

- The plan should be developed in consultation with the individual by a health or social care professional. Where appropriate, family members or carers should be involved in this discussion
- The planning process should include validated measures of depression and physical assessments
- The plan should provide an individual with information and signpost them to services they can access to help manage their physical or psychological needs
- Any decisions should be made collectively between the person and professional. Self-management, in terms of patient education, lifestyle issues and access to community support schemes or services, should be discussed
- The plan should be reviewed annually or when the physical or psychological needs of a person change

This vision will require a change in culture in the dialogue and relationships between health care professionals and people with long term conditions, making the Government's vision of shared care and "no decision about me without me" a reality. Discussions between the person with the long term condition and the professional should take place on an equal footing, recognising the expertise and skills of both. The dialogue should enable and empower people to live with their long term condition, and address the psychological and emotional challenges that they may experience.

National policy-makers

- 1 The Department of Health should ensure that the forthcoming Long Term Conditions Outcomes Strategy guarantees every person with a long term condition the opportunity to engage in a discussion and agree their Plan of Care with a health and /or social care professional. The plan should address their physical and mental wellbeing. The NHS Commissioning Board should measure the extent to which people with long term conditions are able to engage in a Plan of Care consultation and the range of support services available to them.
- 2 The NHS Outcomes Framework, the Social Care Outcomes Framework, the Public Health Outcomes Framework and the Commissioning Outcomes Framework should include indicators designed to assess the level of engagement in and access to a 'Plan of Care', and the depression support services available for people with long term conditions.
- 3 GPs should be better incentivised to check on the mental wellbeing of people with long term conditions through the Quality and Outcomes Framework (QOF). QOF points should be awarded for active targeting and assessment of depression in people with long term conditions.
- 4 The Long Term Conditions Outcomes Strategy should recognise the important role clinical activity, audit and outcomes data plays in driving change. The Department of Health should commit to establishing a working group involving strategic partners, such as the third sector, to investigate new datasets that should be collected to support improvement in care and outcomes for people with long term conditions and depression.
- 5 The Department of Health should undertake urgent research on the most effective interventions for people with long-term conditions and depression as part of the Long-Term Conditions QIPP workstream.

Commissioners and service providers

- 6 The psychological needs of people with long term physical health conditions should be examined by Health and Wellbeing Boards in the Joint Strategic Needs Assessment process.
- 7 Clinical Commissioning Groups should use the Joint Strategic Needs Assessment to commission a complete set of support services for people with long-term conditions and depression. This should include providing access to self management programmes, education materials, counselling, peer-to-peer support and access to IAPT (Improving Access to Psychological Therapy). Clinical commissioning groups should also signpost people with long term conditions to relevant third sector organisations.
- 8 Clinical Commissioning Groups to ensure that service specifications and monitoring arrangements assess access to and the patient experience of psychological services for people with long term conditions. Providers to report on these measures in Quality Accounts.
- 9 Local Education and Training Boards should ensure that health care professionals across primary, community and acute services are provided with training to help recognise the symptoms of depression in people with long term conditions, including how to respond to emotional needs when assessments are carried out and in the attitudes and skills used to engage in open dialogue to meet individual needs within the process of agreeing their Plan of Care. Training supporting the development of an agreed Plan of Care should be included in Continuing Professional Development programmes and incorporated into GP revalidation.



introduction



We are a coalition of charities working on behalf of people with long term conditions. We have a common concern that people with long term conditions who develop depression are not receiving the care and treatment they need. We have come together to call for better detection, management and care of depression amongst this group of people.

Our coalition is made up of Arthritis Research UK, British Heart Foundation, Depression Alliance, Diabetes UK, Macmillan Cancer Support and the National Rheumatoid Arthritis Society.

In this paper we will focus on the links between long term conditions and depression. We will focus solely on depression rather than mental health problems more widely. This is because depression is the most common mental health problem, and it is also the most common mental health problem amongst people with long term conditions.

Depression and long term conditions are a particularly important challenge for the NHS to tackle due to several current factors:

- The ageing population, leading to longer life expectancy but more chronic illness;
- The current financial climate and pressures on public services as well as on individuals themselves;
- Changes to the welfare system removing benefits from some vulnerable groups;
- The opportunities presented by reforms to the NHS of patient-centred care.

We are aware that the Department of Health is developing a Long Term Conditions Outcome Strategy and that this is expected to be published by the end of 2012. We hope that our paper will be useful to the Department in developing that strategy which we feel must include policy on supporting people with long term conditions towards better mental wellbeing.

The Government's current mental health strategy has six key aims, including ensuring that more people will have good mental health and improving the physical health of people with mental health problems. It states one of its objectives as being: "Fewer people with mental health problems will die prematurely, and more people with physical ill health will have better mental health".² This presents a large and broad commitment which in the reality of the NHS may be difficult to implement.

During this key time in the NHS, with substantial structural change underway, it is vital that this large group of people with complex needs are at the centre of enabling greater engagement in their own care, as well as local service planning.

We appreciate the growing recognition of co-morbid depression and long term conditions, such as the recent King's Fund paper on mental health and long term conditions which highlights this issue.¹ In addition, NICE guidelines and quality standards call on healthcare professionals to treat the psychological needs of people with long term conditions. The NICE quality standard for diabetes in adults prioritises care planning and emotional and psychological support services within the ongoing delivery of high quality care³ and the quality standard on patient experience also promotes the need to assess psychological well-being.⁴ There has also been investment in most areas of long term conditions to improve care over recent years. But more must be done to ensure a holistic approach to care and support for people with long term conditions suffering from depression.

We want this paper to make a useful contribution to the Department of Health's Long Term Conditions Outcome Strategy and QIPP (Quality, Innovation, Productivity and Prevention) agenda, as well as highlight to clinical commissioning groups and healthcare professionals the importance of addressing depression in people with long term conditions with appropriate support and services.

We also welcome the opportunity to improve care and services for people with long term conditions and depression presented in the Long Term Conditions Outcomes Strategy, which the Department of Health is due to publish by the end of 2012.

In this paper we have restricted our comments to the health service in England. However we are aware that similar issues face people with long term conditions in the other nations of the UK. The paper has drawn on the work of the Richmond Group^{4a} and Year of Care programme^{4b} (a partnership of Diabetes UK, Department of Health, NHS Diabetes, and the Health Foundation).



depression and long term conditions



What is depression?

Depression affects different people in different ways. The symptoms may range from “lasting feelings of sadness and hopelessness to losing interest in the things you used to enjoy and feeling very tearful or anxious”.⁵ There may be physical symptoms, often tiredness, loss of appetite or aches and pains and the illness can affect people in a mild form through to severe depression with suicidal thoughts. For many people, depression is a chronic (though generally fluctuating) condition and so is often seen as a long-term condition in itself. For most people with depression, treatment and support will be gained via their GP.

Depression affects around 10% of adults in the UK. The World Health Organisation (WHO) projected that the global burden of depression, measured in terms of disability adjusted life-years, would rank second only to coronary heart disease by the year 2020.⁶

What are long term conditions?

Long term conditions (LTCs) are illnesses where the people require on-going medical care to manage and adapt to their health needs over a period of years. This includes a range of conditions and diseases such as heart disease, Type 1 and Type 2 diabetes, cancer, arthritis, asthma and depression. These people are likely to be intensive users of the NHS and their care is a significant function of the health service. According to the Department of Health in England, people with long term conditions account for 31% of the population but use 52% of all GP appointments and 65% of all outpatient appointments. Their figures suggest that an estimated 15.4 million people have a long term condition,⁷ though according to the College of Occupational Therapists, this could be closer to 17 million.⁸

Long term conditions largely affect an older age group. Three out of every five adults over the age of 60 in England have a long term condition.⁹ With the ageing population, these statistics will only increase.

According to the Department of Health, around 70–80% of people with long term conditions can be supported to manage their own condition¹⁰ and this is the desired outcome in many cases.

This is also a group of people that is set to increase substantially. The Government's figures say that three out of every five people aged over 60 in England have a long term condition and that due

to the ageing population the number of people in England with a long term condition is set to rise by 23% over the next 25 years.¹¹

The previous Government introduced a National Service Framework (NSF) for Long term Conditions¹² (including neurological conditions) in 2005. This document introduced a new strategy for caring for people with long term conditions and was necessary because of the current and future strain that treating this large group of people with extensive needs has on the health service. Additionally, there were strategies and plans relating to individual long term conditions, such as the NSFs for diabetes, coronary heart disease and stroke and the Cancer Plan.

The UK economy stands to lose £16 billion over the next 10 years through premature deaths due to heart disease, stroke and diabetes.⁹

Co-morbidity of long term conditions and depression

According to the National Institute for Health and Clinical Excellence (NICE) depression is two to three times more common in people with a chronic physical health problem.¹³ There are a number of reasons for this. Psychological distress is interrelated with serious physical illness and disability, as both cause and consequence.

Contributing factors:

- The effect of pain;
- Fear of the future – on-going illness or premature death;
- Biological effects of the long term condition.

People seeking help for depression face many barriers. Problems accessing help may include:

- Stigma – fear of being seen as having a mental illness;
- Inability to access treatment because of lack of training amongst healthcare professionals / negative attitudes of staff;
- Structure of the health service – the separation of mental health and physical health care;
- Lack of general access to treatments such as talking therapies because of funding issues.

There is an interrelation between long term conditions and depression. People affected by chronic physical illness may develop depression, but also people who have depression may go on to develop a long term condition.

People with mental health problems such as depression tend to have poorer physical health than the rest of the population¹⁴ and rates of long term conditions amongst this group are high. Rates of illness are higher as are death rates. This is due to various reasons partly including higher levels of smoking, obesity and lack of exercise but also due to attitudes of healthcare workers which may mean other physical health complaints are not taken seriously and so problems develop.¹⁵



the evidence on long term conditions and **depression**



It is known that all illnesses have a psychological impact. The impact of the particular illness on the person depends on the individual's perception of the illness as well as its severity.¹⁶

The figures

Depression is two to three times more common in people with long term conditions.¹³ Around 20% of people with long term conditions will develop depression.¹⁷ The combination of on-going physical health problems with depression can exacerbate both conditions, worsening the health of the individual and increasing their healthcare needs. Depression can affect a person's ability to care for themselves, manage medication, manage diet and make other lifestyle choices.

Figures from the WHO show the extent of the problem globally; they suggest that up to 33% of people with cancer will develop depression, 27% of those with diabetes and up to 44% of people with HIV/AIDS.¹⁸ They state, "It is neither a chance phenomenon nor a mere feeling of demoralization or sadness brought on by the hardships of a chronic illness". Patient groups suggest that the figures in England are significantly higher than this.

Over the period 1985-2010 the number of people aged 65 and over in the UK increased by 20% to 10.3 million; in 2010, 17% of the population were aged 65 and over. The number of people aged 85 and over more than doubled over the same period to 1.4 million. Population ageing will continue for the next few decades. By 2035 the number of people aged 85 and over is projected to be almost

2.5 times larger than in 2010, reaching 3.5 million and accounting for 5% of the total population. The population aged 65 and over will account for 23% of the total population in 2035.¹⁹

Disability and multiple health conditions also increase the risk of depression and make successfully accessing treatment more of a challenge.

The Kings Fund report on long term conditions and mental health estimated the cost of care for those with long term conditions and mental health conditions in England to be £8 to 13 billion, with depression being the most common mental health problem. Additionally, studies indicate that depression can increase healthcare costs by between 33% and 169% over a range of long term conditions.¹

Effects of co-morbidity

Depression is known to have a number of effects on the ability of a person to look after themselves and manage their condition. For example, depression can exacerbate the symptoms of diabetes by affecting a person's ability to control their diet or manage their medication. Similarly, most people with osteoarthritis will also have another long term condition, such as lung or heart disease or diabetes. Thus, ensuring they maintain a healthy diet and active lifestyle is important to reduce risks associated with these other conditions.

Furthermore, it has been shown that depressed people are three times more likely not to follow medical regimes than non-depressed people.¹⁶ Stress caused by depression can also directly affect a person's blood glucose levels. The total cost to the health service of each person with diabetes and co-morbid depression is 4.5 times greater than the cost for a person with diabetes alone.²³

People with a long term condition and depression are more likely to need hospitalisation than those with a single diagnosis unless an intervention is made. Depression can affect a person's process of rehabilitation making it harder for a person to recover a decent quality of life. Thus comorbid depression increases hospitalisations and bed days for a person with long term conditions which create an additional cost to the NHS.

The co-morbidity of a long term condition with depression also has serious implications for survival rates. A study has suggested a possible association between depression and cancer deaths.²¹ Research shows that depressed people are also more likely to commit suicide or request physician-assisted suicide. People with heart disease who are depressed have an increased risk of death following heart myocardial infarction compared with those who are not depressed.²²

Barriers to diagnosis

Stigma presents a major barrier to many people who may need help for a mental health problem. They may be unwilling to recognise their own mental health problem because of not wanting to be labelled as being "mentally ill" and this having a negative impact on how they are perceived by family, friends and in the workplace. They may have a perception that people with depression or other such mental health conditions receive a poor standard of care. By concealing their symptoms it is obviously harder to reach a diagnosis.

However, people with long term conditions may also come up against health workers who do not recognise the signs of depression or feel it is a normal response to the already present chronic physical illness. Around 30-50% of depressed people are not recognised as such in consultations²³ and this is even worse amongst people who have a long term condition.²⁴ The current assessment for depression in a person would usually take place following the identification of certain patterns of symptoms. Once these were recognised then various questions can be asked of the person to confirm whether depression is present. This process would normally occur in a GP's surgery and any prescription or treatment would also occur here.

For example, as part of the NICE clinical guideline for the treatment of people with osteoarthritis, GPs are recommended to conduct a holistic assessment of the person which includes giving consideration to their mood.⁹ GPs should screen for depression as well as identifying other stresses in life. Once diagnosed, taking a collaborative approach to depression in this context can aid a reduction in disability and arthritis pain.^{25,26}

Research indicates that it may be the physical features of depression, such as poor appetite, weight loss, sleep disturbance and fatigue, which are misinterpreted.¹⁵ These conditions may also be associated with the LTC, as a side-effect of treatment or seen as a natural response to a diagnosis of chronic physical illness.



depression and key long term conditions



Long term condition	Prevalence of depression	Impact on individual	Access to psychological services
<p>Musculoskeletal conditions (these are conditions of the joints, bones and muscles – including back pain, rheumatoid arthritis and osteoarthritis - along with less common but serious systemic autoimmune diseases such as lupus)</p>	<p>Pain is a common symptom of musculoskeletal conditions. Depression is four times more common for those people in persistent pain than in those without such pain.^{27,28,29,30}</p> <p>It is estimated that around 10.1 million adults consult their GP with musculoskeletal problems each year.³¹ Osteoarthritis pain is associated with an increased risk of depressive symptoms, as a result of its effect on fatigue and disability.³²</p>	<p>Depression affects medical adherence and desire to follow exercise regimes.</p> <p>An analysis of data from the USA found that adults with arthritis are more likely to experience suicidal thoughts than those with healthy joints, 5.6% of people with arthritis had suicidal thoughts, according to the results of their patient health questionnaires. This compared with just 2.4% of those without arthritis.³³</p>	<p>As part of the NICE clinical guideline for the treatment of people with osteoarthritis, GPs are recommended to conduct a holistic assessment of the person which includes giving consideration to their mood.³⁴</p> <p>GPs should screen for depression as well as identifying other stresses in life. Once diagnosed, taking a collaborative approach to depression in this context can aid a reduction in disability and arthritis pain.^{35,36}</p>
<p>Rheumatoid arthritis (a musculoskeletal condition)</p>	<p>Studies indicated that 19% of people with rheumatoid arthritis are formally diagnosed with depression.³⁷</p> <p>People with rheumatoid arthritis and cardiovascular disease have higher depression than people with rheumatoid arthritis and no cardiovascular disease.³⁷</p>	<p>Co-morbid depression and rheumatoid arthritis disproportionately worsen outcomes. Depression is linked with increased pain levels.³⁸</p> <p>Depression has been demonstrated to be an independent risk factor for mortality in patients with rheumatoid arthritis.³⁹</p> <p>A study has shown that 30% of people with rheumatoid arthritis and depression reported suicidal ideation.⁴⁰</p> <p>Depression can result in poor adherence to treatment.³⁷</p> <p>A study reported on a five-year follow-up of patients with RA who had been given NICE-approved psychological therapies early in the course of their illness. The outcome was significantly less use of healthcare resources during the following five years, with significant reductions in admissions, injections, referral for physiotherapy and total healthcare costs.⁴¹</p>	<p>The NICE clinical guideline on rheumatoid arthritis recommends that people with this condition are offered an annual review which includes checking for the development of comorbidities, including depression.⁴²</p> <p>A National Audit Office report on services for people with rheumatoid arthritis showed only 14 per cent of acute trusts provide access to psychological services for all patients who need them, even though depression is common for people with rheumatoid arthritis.</p>

Long term condition	Prevalence of depression	Impact on individual	Access to psychological services
Cancer	About 25% of people with cancer will experience major depression over the course of their illness. ²¹ Macmillan suggest that 49% of people with cancer say they experience depression as a result of their cancer diagnosis. ⁴³	Known to increase death rates.	Macmillan's figures state that 60% of people with cancer who experience depression do not receive any information, advice, support or treatment for this. ⁴³
Diabetes	41% of people with diabetes have depression. It is at least twice as common in people with diabetes as the general population and between 30-50 per cent of cases are undetected. ⁴⁴	Affects medical adherence and ability to control diet.	85% of people with diabetes have no access to psychological support and 37% of people who feel they need specialist psychological support have not been able to access it in the last year as part of the standards of care they should expect. ^{45, 46, 60}
Heart disease	Following acute cardiac events such as myocardial infarction, up to 20% of individuals will have a major depressive episode within a few weeks, and a further 25% experience minor depression or elevated levels of depressive symptoms. Depressive symptoms are present in around 25% of people with congestive heart failure. ⁴⁷ Depression has been associated with a four-fold increase in the risk of heart disease, even when other factors are controlled. ⁴⁸	Affects ability to control diet and physical health routine. Depression is also linked with greater use of health services, poor quality of life and less successful rehabilitation.	42% of cardiac patients are currently provided with rehabilitation and only 16% of these programmes have a psychological component, despite 31% of patients experiencing significant anxiety problems and 19 per cent having depression. ⁴⁹

Other conditions and factors

Alzheimer's disease

Experts estimate that up to 40% of people with Alzheimer's disease suffer from significant depression.⁵⁰

HIV

Depression is twice as common in people with HIV as in the general public.⁵¹ According to the HPA, poor mental health can contribute to increasing sexual risk taking, whilst other studies show that there is a connection between depression and HIV care, treatment, and disease progression. For example, HIV+ women with chronic depression go to their medical visits less regularly and are more likely to progress quickly to AIDS. Studies have also shown that HIV+ women with depression are twice as likely to die as those with few or no symptoms of depression.⁵²

Liver disease

Depression in people with chronic Hepatitis C virus (HCV) is significantly more common than in the general population. Researchers have observed that depressive symptoms in people with hepatitis C infection are commonly overlooked in routine clinical interviews, and that treatment-induced depression compromises the outcome of HCV therapy. Meanwhile, people with liver cirrhosis often demonstrate signs of psychological distress and depression, in relation to the severity of liver disease.

Multiple Sclerosis (MS)

People with MS are almost three times more likely to suffer from major depression at some stage of their lives than people in the general population and there is an increased chance of people with MS committing suicide.⁵³

Muscular Dystrophy

Research shows that parents of children with Duchenne muscular dystrophy have a higher probability of going through a major depressive episode and have significantly lower self-esteem and mastery scores than the national control group.⁵⁴

Respiratory disease

Depression can affect up to 40% of people with respiratory/chronic obstructive pulmonary disease.⁵⁵

Stroke

There is considerable research into the effects of depression on stroke, with the prevalence of post-stroke depression estimated to be as high as 61%. There is also evidence which shows that those with depression recover less well after the stroke, but research indicates that effective treatment for depression enhances quality of life and improves physical, social and emotional functioning.⁵⁶

Older people

One in four older people in the community have symptoms of depression.⁵⁷ Severe depression impairs elderly peoples' lives more than serious medical illnesses, and treatment of depression "has the potential to improve patients' lives in spite of other medical comorbidities".⁵⁸



impact of depression on people with long term conditions



The costs to individuals and their close family/carers can be extreme. Both physical and mental illness can put a huge strain on families and the combination of both conditions can bring some people to crisis point. The management of long term conditions aims to enable a person to maintain a certain and consistent standard of living. When care fails a person may reach a crisis point, a downturn in the person's condition requiring inpatient care. Depression can increase the likelihood of this sort of crisis for an individual.

According to Diabetes UK, one of the most difficult elements for a person to come to terms with when diagnosed is that diabetes is for life.⁵⁹ Though over time, many people will grow to understand and manage the condition well, for others it can lead to emotional distress and depression.

Macmillan states that 45% people with cancer say that the emotional aspects of cancer are the most difficult to cope with, as compared to the practical and physical effects.¹⁹ Diabetes UK reports that 62% of people with diabetes say that they have not developed a care plan which has been decided by discussing their individual needs with their health care professional.⁶⁰

Latest evidence from Ipsos MORI (October 2011) showed that out of 1301 respondents, 47% of people with cancer reported low mood and 49% reported fear that the cancer would come back.^{60a} Work also published recently by Dr James Brennan in Bristol, from a smaller study group of 395 respondents, showed that 45% reported fear or anxiety.^{60b} In both of these reports people also reported extreme fatigue and sleep problems, memory difficulties and loneliness or isolation. All of these issues can relate to anxiety and depression.

There is also a significant impact on the mental wellbeing of carers. Macmillan reports that 46% of carers find that the support they give a person with cancer affects their own mental wellbeing, causing stress, lack of concentration, anxiety and depression.⁶¹

Access to psychological treatments would make a real difference to people with long term conditions and depression but evidence from patient groups suggest that many people are not receiving the care they need. For example in the Minding the Gap report, Diabetes UK found that "85% of people with diabetes do not have access to specialist psychological services, and even where a service is available the waiting time to be seen frequently exceeds three months". A report on rheumatoid arthritis by the National Audit Office found that just 14% of people with rheumatoid arthritis had access to psychological support services.⁶² Macmillan have researched experiences of people with cancer and found similar problems.



opportunities to improve care
for people with LTCs and depression
in the reformed NHS



Public services are currently under huge financial pressure and the NHS, though receiving some political protection, needs to meet a huge demand on limited funds. The reforms to the NHS may present risks to existing good practice while also offering opportunities to do things better. The Government's commitment to publishing a Long Term Conditions Outcome Strategy is undoubtedly also an opportunity to move towards better care and support for people with long term conditions and depression.

Structural change and commissioning

The Government's proposed changes to the NHS will bring about huge changes to the health system structure and commissioning of services. The reforms are intended to enable the NHS to become more productive in the face of the rising costs of caring for the ageing population, the purchase of new treatments and addressing public health needs. The NHS needs to achieve up to £20 billion of efficiency savings by 2015.

At the heart of the plans will be a change to the bodies responsible for allocating resources. Clinical Commissioning Groups, the NHS Commissioning Board and local authorities will take control of commissioning.

Under current commissioning processes, individuals with both physical and mental health needs often fall through a funding gap between physical and mental health commissioners. According to the Royal College of Psychiatrists, "People with physical and mental health problems, whose mental health needs are not addressed, may consume large amounts of physical healthcare resources, both in the primary and secondary sector." They go on, "As commissioning arrangements in England change, there is a real opportunity to provide needs-led integrated services for such people".^{62a}

The Department of Health's Quality, Innovation, Productivity and Prevention (QIPP) programme has been devised to ensure that each pound spent in the NHS is used to bring maximum benefit and quality of care to patients. At a regional and local level, SHAs have been developing integrated QIPP plans focusing on raising quality and productivity. These are supported by the national QIPP workstreams which are producing tools and programmes to aid successful local implementation.⁶³ The long term conditions workstream aims to "reduce unscheduled hospital admissions by 20%, reduce length of stay by 25% and maximise the number of people controlling their own health through the use of supported care planning. The workstream aims to replicate this performance nationally by 2013/14." The workstream includes a focus on promoting self care and shared decision-making as a means to improve care and make efficiency savings.

There are also other structures which may be useful for promoting the needs of people with long term conditions and depression. Health and Wellbeing Boards (HWBs) will be a forum for local commissioners across the NHS, public health and social care, elected representatives, and representatives of HealthWatch to discuss how to work together to improve the health and wellbeing outcomes of the people in their area.⁶⁴ Furthermore, the National Learning Network which brings together emerging health and wellbeing boards to build and share an understanding of how Health and Wellbeing Boards can be effective in improving outcomes, include a focus on long term conditions.

Public health measures

Responsibility for public health is changing in England with local authorities taking the lead on promoting public health at local level and Public Health England at a national level.⁶⁵ Under this transfer of responsibility there is huge scope to better meet the needs of people with long term conditions at a local level. Health promotion, information provision and support services will be vital in supporting the needs of many hard to reach groups such as older people and those living on their own who may lack the support of friends or family to manage their medicines or lifestyle issues. People who may find it difficult to manage their medication, diet and exercise and who may lack company and be lonely should be targeted for support.

Public health promotion should also address the social reasons that some people secure better outcomes from the NHS than others, for example by recognising that for some people accessing care will be seen as a consumer right for which they will fight and lobby while other people may be more passive and not win the same level of care.

Assessment, early diagnosis and access to support for depression

Given the prevalence of depression amongst people with long term conditions it is vital that healthcare staff are proactive about looking out for symptoms following the diagnosis of a long term condition and throughout the care of the person.

Macmillan suggest that while 49% of people with cancer want or need information, advice or support about the emotional aspects of a cancer diagnosis, 41% of these people are not able to get this help.²⁹ Furthermore, only 14% of people with diabetes say they were offered emotional or psychological support from a specialist healthcare professional service they needed.⁵²

The King's Fund has recommended that "strengthening the interface between mental and physical health care, particularly for older people and people with long term conditions" is one of the key ways the health service could become more efficient.⁶⁶ A report for the Inquiry into the Quality of General Practice in England⁶⁷ examined the role of GPs in managing people with long term conditions. The research found that despite significant improvements in many areas within general practice, an opportunity had been lost to redesign primary and community care to better meet the needs of those with long term conditions.⁶⁸

One of NICE's key priorities for the implementation of its guidelines in this area, "Depression in adults with a chronic physical health problem"⁶⁹ is identifying depression through using a two question screening tool. This approach has already been used as part of the Quality and Outcomes Framework (QOF)¹ for people with coronary heart disease and diabetes and the guidelines promote extending this current practice to other settings and a wider patient group.

In terms of depression and heart disease, the British Heart Foundation is keen to see psychological support and wellbeing viewed as part of a broader package of rehabilitation and reablement support for people after a significant heart event. This should not be a standalone service – otherwise there is the risk of reinforcing the silos between physical and mental health services – rather this must be integrated into cardiac rehabilitation programmes. Diabetes UK believes that maintaining psychological health to support people with diabetes to self-manage through education, information and emotional support can help individuals develop the skills to cope with the challenges of daily decision-making and improve coping and well-being, counselling, emotional and psychological support services are an essential part of routine diabetes care and specialist services for those with more complex clinical and psychological needs.

Additionally, NRAS is pushing for depression to be screened more routinely during holistic annual reviews with multidisciplinary teams which should address a person's quality of life including their social roles and work, along with pain and mood.

The Government's welcome investment through the Improving Access to Psychological Therapies programme in the treatment of depression through talking therapies has been a key commitment to improving access to care. However, it is important that these therapies are made available to all who need them and that people with long term conditions are not excluded. The benefits are clear, for example, amongst people living with angina; it has been estimated that "40% of admissions and half of revascularisations can be avoided by providing a NICE-approved psychological therapy".⁷⁰

Workforce issues

Some people may develop depression quickly following the diagnosis of a long term condition, for others it may occur years into the illness. It may develop as a consequence of the illness or be completely unrelated; however, the increased prevalence amongst this group means that healthcare professionals need to be alert to depression in people with long term conditions.

Training for the frontline staff, principally in primary care, who regularly work with people with long term conditions is vital in ensuring that depression is actively monitored for and correctly identified where present. In the first instance it will be GPs and nurses who are most in contact with this group of people. They need to ensure that talking with people with long term conditions about the signs of depression becomes a standard part of their care and that if depression is diagnosed that treatment and support is offered. The challenge is to maintain an awareness of the person's holistic needs over a long period of time.

Healthcare professionals should be trained to discuss emotional and psychological issues with people with long term conditions in a non-judgmental manner, provide advice and information about the support available, along with supporting the implementation of the desired support or service. Training should be made part of continuing professional; development programmes and the GP Revalidation process.

There are also other healthcare professionals who may be involved in the care, depending on whether the individual moves beyond the primary care setting or is being cared for by a specialist team. If people with long term conditions are having regular check-ups or treatment in hospital this provides another opportunity for staff to monitor their mental wellbeing. While the primary focus may

be on treating the physical symptoms of the long term condition, the needs of the individual should be viewed at every possible interaction in a broader sense to ensure symptoms of depression are not missed.

Liaison psychiatrists specialise in the interface between physical and psychological illness: “They have expertise in the treatment of psychological symptoms that develop in the context of physical disease and also physical symptoms for which there does not appear to be an underlying organic explanation (so-called ‘medically unexplained symptoms’). Most liaison psychiatry has traditionally been hospital-based, but as health services change, with more individuals receiving their treatment in primary care, liaison services can provide valuable support to GPs and Tier 2 services, in addition to acute hospital work.”¹³

Data collection

Systematic measurement of clinical activity and health outcomes as part of routine data collection in the NHS has the potential to be a powerful lever for improving healthcare quality.⁷¹ We would like the Long Term Conditions Outcomes Strategy to recognise the important role clinical activity and outcomes data plays in driving change. In the areas of long term conditions and depression the Department of Health should commit to working with partners to investigate what more can be done to tackle data poor areas. For example, many musculoskeletal and rheumatological services are provided as outpatient appointments and there is limited data collected as part of routine clinical care.





getting the balance right: examples of good practice



This section highlights the range of support and initiatives patient groups are providing to help people with long term conditions and depression.

Guidance for healthcare professionals

- The British Heart Foundation has produced a GP factfile on depression which outlines the key issues doctors need to know about how to identify and manage depression amongst people with heart conditions.
- Arthritis Research UK publish three regular report series for healthcare professionals. These include “Hands On” which provides practical advice for GPs on the management of patients with arthritis.
- Diabetes UK’s primary care network provides information and support factsheets within Diabetes Update for clinicians and staff about managing diabetes and depression.
- Depression Alliance coordinates a national network of peer-led self-help groups, who each provide local GP’s with information about their services. This enables GP’s to refer patients to a sustainable and long term source of mutual support, uplifting social activities and information on depression

Support and information for people with long term conditions, carers and health professionals

- Arthritis Research UK provides research-based information for patients including specialist advice for young people affected by arthritis. Patients can also search on their website for their condition coupled with the symptoms of depression to find information. They are undertaking research on an intervention to help rheumatology professionals provide psychological support to patients with inflammatory arthritis, as well as investigating the management of musculoskeletal conditions in general practice, including management of depression.
- NRAS runs a helpline and provides peer-to-peer support for members of the public who feel depressed. The NRAS publication ‘Managing Well: Living with Rheumatoid Arthritis’ contains a section on low mood and depression, it also includes information about recognising the signs of depression.
- Diabetes UK runs a dedicated Careline for all people with diabetes and their families and carers. This service provides advice and guidance for people following diagnosis on managing their emotional response.⁷² Information and education resources about living with diabetes, enabling self-management and depression are also available.
- British Heart Foundation’s main support service is the Heart Helpline, which is for any heart related query but does include specialist psychological support. They also publish a patient information booklet on stress and the heart.⁷³

- Macmillan focus their research on improving the quality of life for people affected by cancer and turning the results into practical solutions and better quality services. They also assess their services to understand what types of care and support work best. They provide a wealth of information about the emotional impact of cancer.
- As well as providing support via their website and helpline NRAS support local patient groups to help people with RA to manage their condition through peer-support. NRAS also have a new patient commissioning toolkit.
- British Heart Foundation fund an annual audit of cardiac rehabilitation. Psychological support is a component of a good quality rehabilitation service and the audit collects data on this. The most recent audit⁷⁴ suggests that only around a fifth of eligible heart patients are getting this support.
- Depression Alliance provides a range of information via their website, through leaflets and a quarterly magazine. They host an online support forum DA Talk, and also the online resource What you should know about depression, which offers a wealth of information about choosing suitable treatments. They coordinate a national network of peer-led self help groups providing mutual support and information for anyone affected by depression and long term conditions, as well as a penfriend service for those seeking to share one-to-one support.

Medical research

- Arthritis Research UK are currently funding research into “What helpful psychological support patients in England with inflammatory arthritis have access to as part of their clinical care”. The project will develop a proposal for an intervention to help rheumatology professionals provide psychological support to patients with inflammatory arthritis.
- British Heart Foundation fund researchers to investigate ways of improving the care and treatment of patients with heart disease. Professor Andrew Steptoe’s team⁷⁵ has discovered that in some patients, intense episodes of anger and stress occur in the hours immediately before the onset of chest pain and they are now studying the biology behind these effects. In another new study Professor Steptoe and his team will monitor patients admitted to hospital with a heart attack to understand why some patients become depressed and anxious after the heart attack while others do not. They will also look at the way in which a person’s emotional response to the heart attack may influence the success of their rehabilitation.
- Diabetes UK spends over £5 million on diabetes research funding to identify how to improve the quality of care of those living with the condition



our vision and recommendations



When a person is diagnosed with a long term condition it can be devastating news. When a person is unable to carry out their everyday activities or have to change their lifestyle due to a long term condition, it can have a devastating impact. Services for people with long term conditions must take into account the emotional and psychological impact of being diagnosed or living with a long term condition.

We would like every person with a long term condition to be treated for both their physical and psychological symptoms in equal measure, recognising the detrimental impact depression can have on the health outcomes and quality of life for those with long term conditions.

It is essential that the implementation of any strategy to involve people with long term conditions in the planning of their care, especially around emotional and psychological issues, does not become a 'tick box exercise' for either the NHS or front line staff. Simply having a Plan of Care, although helpful, will not achieve the outcomes required for people with long term conditions. This is a complex issue and therefore requires a comprehensive approach.

Our **vision** is for:

Every person with a long term condition to be enabled to engage in agreeing a 'Plan of Care' in conjunction with a health and or social care professional through a planning process which assesses their physical and psychological needs equally.

- The plan should be developed in consultation with the individual by a health or social care professional. Where appropriate, family members or carers should be involved in this discussion
- The planning process should include validated measures of depression and physical assessments
- The plan should provide an individual with information and signpost them to services they can access to help manage their physical or psychological needs
- Any decisions should be made collectively between the person and professional. Self-management, in terms of patient education, lifestyle issues and access to community support schemes or services, should be discussed
- The plan should be reviewed annually or when the physical or psychological needs of a person change

This vision will require a change in culture in the dialogue and relationships between health professionals and people with long term conditions, making the Government's vision of shared care and "no decision about me without me" a reality. Discussions between the person with the long term condition and the professional should take place on an equal footing, recognising the expertise and skills of both. The dialogue should enable and empower people to live with their long term condition, and address the psychological and emotional challenges that they may experience.

National policy-makers

- 1** The Department of Health should ensure that the forthcoming Long Term Conditions Outcomes Strategy guarantees every person with a long term condition the opportunity to engage in a discussion and agree their Plan of Care with a health and /or social care professional. The plan should address their physical and mental wellbeing. The NHS Commissioning Board should measure the extent to which people with long term conditions are able to engage in a Plan of Care consultation and the range of support services available to them.
- 2** The NHS Outcomes Framework, the Social Care Outcomes Framework, the Public Health Outcomes Framework and the Commissioning Outcomes Framework should include indicators designed to assess the level of engagement in, and access to, a 'Plan of Care', and the depression support services available for people with long term conditions.
- 3** GPs should be better incentivised to check on the mental wellbeing of people with long term conditions through the Quality and Outcomes Framework (QOF). QOF points should be awarded for active targeting and assessment for depression in people with long term conditions.
- 4** The Long Term Conditions Outcomes Strategy should recognise the important role of clinical activity, audit and outcomes data plays in driving change. The Department of Health should commit to establishing a working group involving strategic partners, such as the third sector, to investigate new datasets that should be collected to support improvement in care and outcomes for people with long term conditions and depression.
- 5** The Department of Health should undertake urgent research on the most effective interventions for people with long-term conditions and depression as part of the Long Term Conditions QIPP workstream.

Commissioners and service providers

- 6 The psychological needs of people with long term physical health conditions should be examined by Health and Wellbeing boards in the Joint Strategic Needs Assessment process.
- 7 Clinical Commissioning Groups should use the Joint Strategic Needs Assessment to commission a complete set of support services for people with long term conditions and depression. This should include providing access to self management programmes, education materials, counselling, peer-to-peer support and access to IAPT (Improving Access to Psychological Therapy). Clinical Commissioning Groups should also signpost people with long term conditions to relevant third sector organisations.
- 8 Clinical Commissioning Groups to ensure that service specifications and monitoring arrangements assess access to and patient experience of psychological services for people with long term conditions. Providers to report on these measures in Quality Accounts.
- 9 Local Education and Training Boards should ensure that health care professionals across primary, community and acute services are provided with training to help recognise the symptoms of depression in people with long term conditions, including how to respond to emotional needs when assessments are carried out and in the attitudes and skills used to engage in open dialogue to meet individual needs within the process of agreeing their Plan of Care. Training supporting the development of an agreed Plan of Care should be included in Continuing Professional Development programmes and incorporated into GP revalidation.



conclusion



It is clear that during this crucial period of reform in the NHS there are risks as well as opportunities for improving the care of people with long term conditions and depression. We want to see the opportunities maximised to use new structures and procedures in the NHS for the benefit of this huge group of people. Prevention and self-management are key in reducing the impact of these diseases on individuals and society. Access to psychological therapies is also particularly important for this group and prioritising investment in this area will undoubtedly bring long term benefits.

This report has shown that there are some specific challenges in reaching these patients and ensuring they receive appropriate care. However, as a coalition we believe we have the knowledge and experience to advise on how best the NHS can meet these challenges. We are already working directly with people with long term conditions to provide information and support to help them face the day to day issues of living with long term conditions and depression and we want to work in partnership with the NHS to ensure that the services and treatments are in place to back this up.

We look forward to working together with the Government to address these issues and priorities.



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