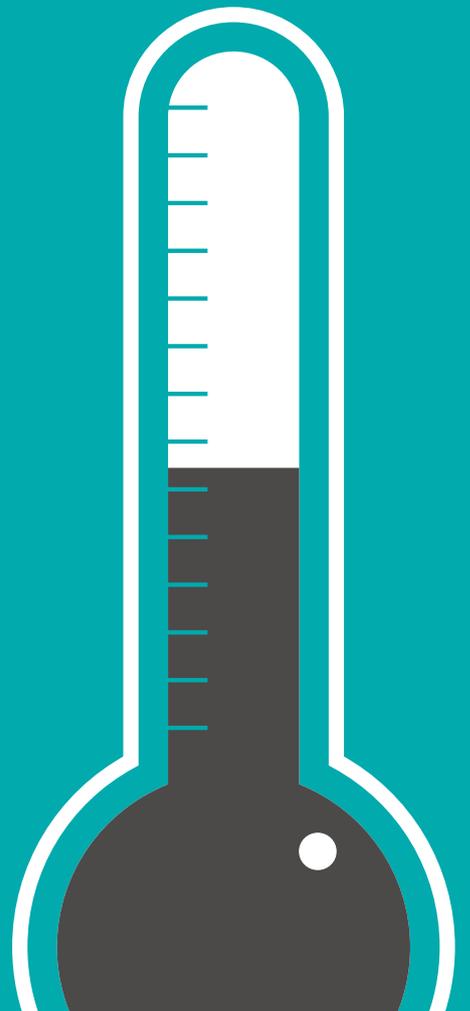


Vital signs

Taking the temperature of health
and care services for people
living with long term conditions.

A report by The Richmond Group of Charities
March 2015



About The Richmond Group of Charities

The Richmond Group of Charities is a coalition of ten of the leading health and social care organisations in the voluntary sector. Our members are:



We work together as a collective voice to better influence health and social care policy, with the aim of improving the care and support for the 15 million people we collectively represent.

Our work is focused on five themes:

- Coordinated care
- Patients engaged in decisions about their care
- Supported self-management
- Prevention, early diagnosis and intervention
- Emotional, psychological and practical support

More information about our work is available at:
www.richmondgroupofcharities.org.uk

If you have any questions about The Richmond Group of Charities, its work or this report, please contact Dr Charlotte Augst, The Richmond Group Partnership Manager at caugst@macmillan.org.uk or on 020 7091 2091

The ten leading health and care charities come together in the Richmond Group to work on behalf of people with ongoing health issues and have unique insights into how they experience their care. The Richmond Group of Charities has the expertise and commitment to help improve the quality of care for those living with long term conditions.

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Over the next five years the real test of Government and NHS leaders at all levels of the system will be whether the gaps we highlight here become a thing of the past and how local services are held to account. This is the bench mark by which we will be judging their success.



70%

**Long term conditions
account for 70% of
hospital bed days.¹**

Introduction

There are 15 million people living with at least one long term health condition in England today, and £7 in every £10 spent on health and social care is spent on managing these conditions. Long term conditions account for half of all GP appointments and 70% of hospital bed days.¹

As a group of patient charities, we know that whether someone is living with a long term condition, is recovering from a serious illness, or dealing with a life-changing diagnosis, good care improves lives and saves money.

In 2012 we published our first joint report *'How to deliver high-quality, patient-centred, cost-effective care'* setting out what matters most to people living with long term conditions, their families and carers:

- Prevention, early diagnosis and early intervention
- Patients engaged in decisions about their care
- Supported self-management
- Emotional, psychological and practical support
- Coordinated care

Our conclusions were firmly rooted in the experiences of the people we represent and drew on our extensive collective evidence about what works best and where action was most needed to ensure a sustainable NHS for the future.

In this report we have returned to these themes to look at where we are now. We have brought together information and evidence from across the system to provide a unique snapshot of the current gaps in care for those living with long term conditions in England today.

While a huge amount of excellent care is provided by many staff, unfortunately the results do not make encouraging reading. Far too many people still have not got access to the best of what the NHS can offer, and suffer as a result. This is costly for the patient and the NHS. Too often we are cutting off limbs rather than helping people with diabetes to stay well or sending people home after a heart attack without the support they need. Every year almost 1,200

people die as a result of their asthma – two thirds of these deaths are potentially preventable.²

Getting this right is about tried and tested solutions, and there is growing consensus about what works.^{3,4,5} However, despite many excellent examples of services leading the way in person-centred care, much of the system has yet to get to grips with supporting and enabling people to live well.

From our unique position we understand how important the NHS is to people living with long term conditions. The state of care is inconsistent and not enough people are getting the care they are entitled to. With long term conditions driving so much hospital and GP activity it is a significant cause of the cost pressures the NHS is facing and will continue to face going forward. As winter pressures reveal, the system can no longer put off getting the basics right. The scale of the problem is just too big and we've reached a tipping point where business as usual is not an option. It's important politically and it's important for the sustainability of the NHS in the run up to the next election.

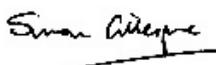
The NHS's Five Year Forward View has set out a road map that we strongly support. However there is a great deal of work to do to turn vision into action that changes the lives of people living with long term conditions for the better. The Richmond Group of Charities has the expertise and commitment to help deliver the necessary changes. Over the next five years the real test of the Government and NHS leaders at all levels of the system will be whether the gaps we highlight here become a thing of the past and how local services are held to account. 15 million voters with long term conditions are experiencing day by day the challenges to getting good NHS care. That is the political challenge.



Tom Wright
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Kay Boycott
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Simon Gillespie
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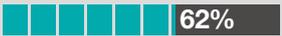
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Prevention, early diagnosis and early intervention

PREVENTION: THE FACTS



Of every 100 adults, 62 are overweight or obese, increasing the likelihood that they will suffer from stroke, coronary heart disease, Type 2 diabetes, high blood pressure, musculoskeletal disease and cancer.⁶

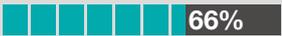
Potentially preventable...



of cases of Alzheimer's...⁷



cases of cancer...⁸



of deaths from asthma attacks...²



of cases of cardiovascular disease...⁹

Urgently treating people who have a minor stroke or a TIA could reduce their risk of having another one by 80%.¹⁰

Prevention

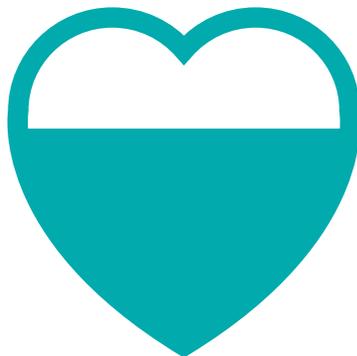
Too many people in England are living with, and dying from, conditions that could have been prevented, including heart disease, stroke, cancer, respiratory illnesses and Type 2 diabetes.

Prevention is better than cure, whether it is stopping a condition occurring in the first place, stopping conditions getting worse, limiting symptoms, or reducing the risk of one condition leading to the development of another. Encouraging and supporting people to adopt healthy behaviours, identifying physical and mental health problems early and enabling people to manage them effectively once diagnosed will help everyone to live as healthily as possible for as long as we can.

The current impact of preventable illness on people's lives and the health system is immense.

In our recent report on prevention *'What is preventing progress?'*, the Richmond Group of Charities argues that stronger political leadership, within and outside the NHS, is needed to make prevention a priority and take comprehensive action before the challenges facing our health services worsen.

Some communities are at a particularly high risk of both physical ill health and of dying early. People in the most deprived neighbourhoods will die on average seven years earlier than those in the richest areas.¹¹ The most socio-economically disadvantaged groups in our society are 60% more likely to have a long term condition than the most advantaged, and are more likely to experience more severe cases of these diseases.¹²



Around a THIRD of people with high blood pressure remain undiagnosed.¹³



Connie Johncock, 25, Kent

“I found a lump when I was 22. I knew I was young to get breast cancer, but my grandmother was diagnosed with the disease in her early 30’s so I didn’t want to take any chances.

My GP dismissed my concerns as nothing, telling me I was too young to worry, 11 months later things had got worse and my boyfriend insisted I go back. One year after I had first visited my GP, I found out I had breast cancer. One month later, I found out my cancer had spread and was incurable.

If I had been diagnosed from the start, I would be living the life I planned; finished my degree to be a qualified nurse, travelled the world, just being the care free Connie I once was and never having to look at my watch waiting for the day my time is up.”

Early diagnosis

Diagnosis of a long term condition as early as possible makes a dramatic difference to a person’s chances of survival and to the quality of life they can expect to enjoy. But we still have a long way to go in providing consistent access to early diagnosis.

Late diagnosis can be a result of people not being aware of symptoms and of GPs and others missing signs. For example, nearly a third of people suffering from neurological conditions had to see their GP five times or more before being referred to a specialist, and 40% had a wait of more than 12 months between first identifying symptoms and seeing a specialist.¹⁴

The NHS Health Check programme, which should offer a health check to all adults between 40 and 75 years old every five years, provides a real opportunity to identify people early who are at risk of developing heart disease, Type 2 diabetes, stroke and kidney disease, and to provide them with the right support to help reduce their risk.

After a slow start the numbers of people offered a health check is now increasing, but progress is much slower in some areas than in others.

Last year while nearly half of eligible adults in Kingston-upon-Thames were offered a health check, in Croydon the figure was less than 1%.¹⁵ The proportion of people who take up the appointments is low and needs to increase: only half of those offered a check last year actually took it up.¹⁶

The prize is potentially great. The Health Check programme could prevent an estimated 1,600 strokes and heart attacks and 4,000 cases of Type 2 diabetes every year, and lead to an earlier diagnosis of at least 20,000 cases of Type 2 diabetes and kidney disease.¹⁷

Early diagnosis also makes a dramatic difference to the life chances of cancer patients. For example, more than 93% of people with bowel cancer survive for at least five years if their tumour was diagnosed at an early stage, compared with only 7% of people whose bowel cancer was diagnosed at a late stage.¹⁸ But the proportion of people who are diagnosed with cancer at an early stage varies significantly between local areas, for example there is a threefold gap between the highest and lowest performing CCGs for colorectal cancer.¹⁹

EARLY DIAGNOSIS: THE FACTS

500,000

Estimated number of people with undiagnosed Type 2 diabetes.²⁰

12.5%

One in eight people over 35 years has Chronic Obstructive Pulmonary Disease (COPD) that has not been properly identified.²¹

>50%

More than half of people living with diagnosed COPD had symptoms for six to ten years before diagnosis.²²

33%

Only 33% of people with schizophrenia are offered a comprehensive physical health check,²³ despite this group being at increased risk of dying from conditions such as heart disease.²⁴

80% of amputations resulting from diabetes could be avoided with access to the right care and support.²⁵

Early intervention

Once someone has been diagnosed with a health condition, providing them with prompt access to the right support and treatment can minimise pain, distress and disability. It will also reduce their chances of complications or crises which require more intensive care.

For example, early intervention services have shown to halve detentions of patients with psychosis under the Mental Health Act (from 44% to 23%).²⁶

Only if we move away from short term interventions focusing on complications and crisis and adopt a truly preventative approach to health and care can we reduce the avoidable suffering that is a reality for so many people and their families.

Patients engaged in decisions about their care

There is rarely a single right response in medicine, and healthcare is often about weighing up the advantages and disadvantages of the options available. We are all individuals and everyone experiences their condition differently. So putting together the right approach is a very personal process that only works when people are fully involved in making decisions about their treatment and care.

However the reality for too many people living with long term conditions is that they are still treated as passive recipients not equal partners in their care. Far too few patients are given the opportunity to articulate their needs, agree priorities and set goals or participate in decisions through care and support planning.

One third of patients in general practice say they are not fully involved in decisions about their care.²⁷



Norah Taggart, 84, Hastings

Norah has heart failure. Her body has twice retained a significant amount of excess fluid, which is a symptom of her condition. The first time she spent three weeks in hospital and was connected to an intravenous drip. The second time she decided, after discussions with her nurse, that she really wanted to stay at home.

“It was just so much more comfortable. It’s all the little things, like being able to go to the loo or to bed when you want, without waiting around.

I used to feel guilty about my husband visiting me each day in hospital too. He was 84, his hips had been done, so it wasn’t easy for him to get around, and trying to park at the hospital was a nightmare. I felt much better knowing he didn’t have to cope with all that too.

The decision to be treated at home was easy. I had a very good relationship with Caroline, my community heart failure nurse, and already knew a lot about how to monitor my condition. I discussed my preference with her, and with Chris, the IV nurse that came to my home. Chris expanded on the information I had already been given so together we could make it work at home.”



PATIENT DECISIONS: THE FACTS



44%

44% of adult inpatients say they are not sufficiently involved in decisions about themselves.⁷⁵



>60%

More than 60% of people with Type 1 and Type 2 diabetes report not having discussed their personal needs with a healthcare professional when developing their care plan.²⁸



23%

23% of people living with neurological conditions felt they were not fully involved in making choices about their care and treatment.²⁹

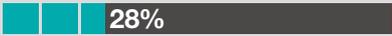


57%

Only 57% of people detained under the Mental Health Act had been involved in decisions about their care planning and risk assessment.³⁰

More than one in four (27%) people living with dementia report not being involved in decisions about their care.³¹

INFORMATION AND CHOICE: THE FACTS



28% of cancer patients were either not given any information or were given written information that wasn't easy to understand.³²



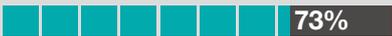
Less than half of elderly care services and only a third of neurology services have information about Parkinson's in their clinics, despite this being recommended good practice.³³



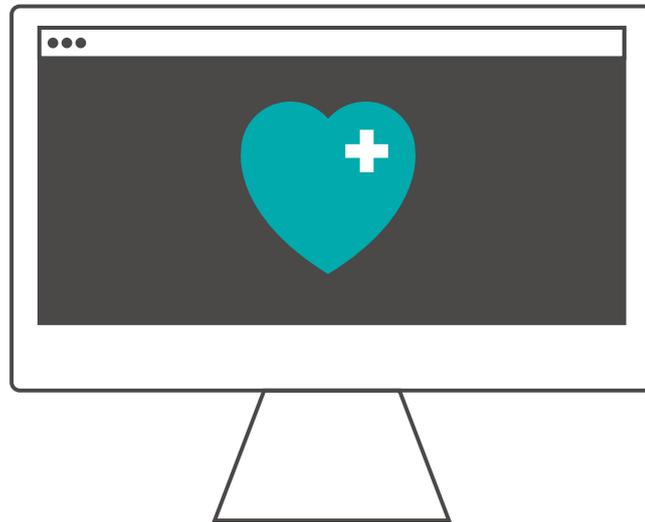
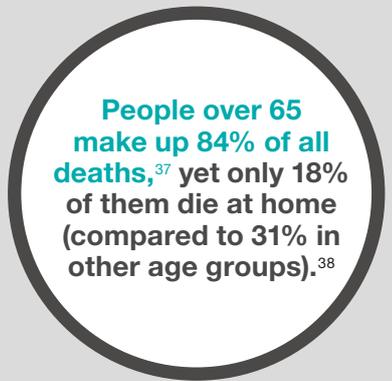
Of the information packs given to stroke survivors, only 40% of people said they were easy to understand, and 60% said they did not contain good information on local services.³⁴



Only four in ten (41%) relatives of people who had died from cardiovascular disease said their loved one was given enough choice about where they could die.³⁵



73% of people with cancer would prefer to die at home, but fewer than a third (30%) are able to do so.³⁶ This amounts to 100 people per day dying in hospital against their wishes.⁴¹



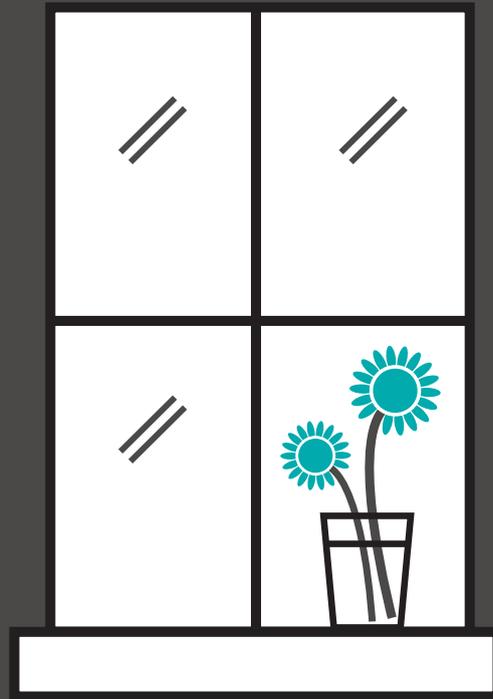
Four out of five patients still don't have access to their medical records online,³⁹ despite a Government pledge to give access to all by March 2015.⁴⁰

For patients to fully engage in making decisions about their care they need to be provided with the right information and support to apply to their individual circumstances. But people continue to report problems with accessing and understanding information about their conditions and about their care and treatment.

We also know one of the choices that patients truly value is having a say about where they are treated or cared for. Yet despite successive governments' ambitions, large numbers of patients and families

are still not being treated where they choose, particularly when it comes to where they die.

It is estimated that the NHS spent £137 million on hospital care at the end of life for cancer patients alone in 2012. The equivalent cost of looking after these people in their own home – including social care – would have been £68.1 million.⁴¹ Building care around the expressed wishes and needs of patients is not an expensive luxury. It is the only way we can truly ensure we are providing a value-for-money system that avoids unwanted or inappropriate care.



Each day,

100

cancer patients who said
they wanted to die at home,
in fact die in hospital.⁴¹

Supported self-management

People with long term conditions spend only a few hours a year interacting with clinicians and more than 99% of their lives managing their conditions themselves or with family.⁴² Supporting people to cope better and to become more knowledgeable and independent means that clinicians need to work with patients differently. Providing good information and support so that people can better manage themselves improves health outcomes and patients' experiences of care, and reduces demand for health and care services.^{43, 44}

But provision of support for people to better cope themselves remains patchy. A recent survey of people with dementia found that one third of people (35%) would like more care, support and services to do things in the community, including more opportunities to participate and help to attend activities through a befriender.⁴⁵

Enabling people to be more in control on a day to day basis requires local health and care services to recognise the importance of flexible learning, education and training opportunities for patients. However access to and uptake of these opportunities remains woefully poor.

Only 1.6% of people with diabetes attended structured education courses that meet NICE standards.⁴⁶

People tell us that they want to understand better how they can live well with their conditions, and it is in the interest of the health and care system to increase people's independence and to try to support them to stay as well as possible. Despite this, providing good information, education and support for self-management is still not part of mainstream service provision.



Nick Guerin, 29, Cheshire

“Managing diabetes is like walking a tightrope. You are trying to keep your blood sugars in balance – without ‘falling off’. The problem is, people start their lives with diabetes with one foot on the high wire and no tools or guidance on how to reach the other side.

After 20 years of living with diabetes, I didn't think I could be told anything about diabetes that I didn't already know... and I was wrong.

A diabetes education course gave me the first opportunity to really understand my condition and make decisions about all

aspects of my life in a realistic way. This gave me the opportunity to regain the reins and left me in charge of my condition, rather than diabetes being in charge of me.

But I was lucky. I know that the vast majority of people with diabetes have not been given the opportunity to attend a course to learn about their condition. This is unacceptable, especially when so many of them are keen to learn to manage better themselves.

Education has massively improved my quality of life. With a two year old child, it has given me renewed energy to be the Dad I want to be.”



ONLY 48%

of people with schizophrenia
had been given information
about their medication and **only
39%** felt it was provided in a way
they could understand.⁴⁷

SELF-MANAGEMENT AND ACCESS TO INFORMATION: THE FACTS



45%

Only 45% of eligible patients received cardiac rehabilitation. This is a programme offering physical, social and psychological help for patients to get back to everyday life as soon as possible and prevent another cardiac event.⁴⁸

<17%

Less than 17% of people newly diagnosed with Type 2 diabetes and 4% of those with Type 1 diabetes were offered skills training.⁴⁶

50%

Around half of patients who had a mini stroke (Transient Ischaemic Attack or TIA) received little or no information about the changes they could make to reduce their risk of further TIAs or stroke.⁴⁹

73%

73% of people over 75 with osteoarthritis have had no discussion with a health professional about what they could do to prevent it from getting worse.⁵⁰

Emotional, psychological and practical support



Patricia, 49, London

Patricia used to work in London in a high-powered job. Then she suddenly had a stroke. She still can't quite believe it happened to her.

"I was rushed to a specialist stroke unit where I received life-saving treatment. But I was left paralysed down one side, and the stroke also affected my speech.

In hospital, I received occupational therapy and physiotherapy, but once I was discharged there was a two-month gap without any therapy, support or information. I was expected to go it alone in a depressed and debilitated state.

I received no help from professionals at first; they didn't understand my emotional state. When I cried, they didn't know what to do; despite the fact that I had been told by them that a right-sided stroke would directly affect my emotions. I also found it really hard to talk about the stroke with friends and family. I still don't like to burden them with it.

The stroke was such a shock at my young age, I'm still struggling to accept it. But the counselling I now receive helps; as does performing my poetry and talking to nurses and companies about my stroke journey."

Living with a serious health condition can sometimes be overwhelming and stressful. As well as the mental and physical symptoms, a condition might impact on everything from work and finances to relationships and family life. At times like these, practical help, good advice and a strong support network make a huge difference.

Getting the right emotional, psychological and practical support at the right time can make all the difference, yet too many people living with a long term condition are denied the help they desperately need.

Physical and mental health problems interact with and exacerbate one another. Physical ill health can place people under immense emotional and psychological strain, doubling or tripling the chance that a person will suffer from a mental health problem,⁵¹ particularly anxiety and depression. Having a serious mental illness can also increase your risk of certain physical health conditions.

People with both physical and mental health problems suffer from poorer outcomes, in part because services are not designed to meet multiple and complex needs.

PHYSICAL AND MENTAL HEALTH NEEDS: THE FACTS

2x

Having depression doubles the chances a person will die within five years of heart bypass surgery.⁵²

People with diabetes are two times more likely to be diagnosed with depression.⁵³

60%

Six in ten stroke survivors experience depression.⁵⁴

61%

61% of people with dementia have felt depressed or anxious recently.⁵⁵

37%

Around a third of people diagnosed with breast, colorectal or prostate cancer or non-Hodgkin lymphoma five years previously experience anxiety or depression. More than one in eight of those diagnosed up to five years previously report moderate to extreme anxiety and depression.⁵⁶

8x

People with chronic heart failure are eight times more likely to die within 30 months if they have depression.⁵⁷

36-38%

People with diabetes who also had depression were 36-38% more likely to die over a two year period.⁵⁸

Yet too often, people with long term physical health conditions cannot access the emotional and psychological support needed to help them manage their condition. Less than 20% of patients receiving cardiac rehabilitation took part in a group psychological discussion and just 2% talked with an individual counsellor.⁵⁹

Living with a long term condition can also present some very practical challenges and changes in someone's life. But access to advice and practical help is often very limited.

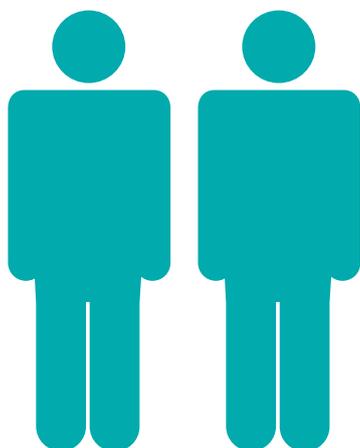
In particular long term conditions place a significant financial burden on individuals and their families, and many do not have access to practical support, such as financial guidance to help them, increasing their risk of ill health and deterioration.

Meanwhile, although unpaid carers provide a huge amount of support for people with long term conditions, too many carers are unable to access information or practical help for themselves or the person they care for.

There are 6.5 million carers in the UK,⁶⁰ and the number is set to rise to nine million by 2037.⁶¹ Unpaid carers provide care worth an estimated £119 billion each year,⁶² which is more than the entire NHS budget for England in 2015/16. For many this care work is being carried out on top of paid employment⁶³ while some are forced to leave their job. For example, one in ten family members of heart attack survivors has had to give up work to look after a loved one.⁶⁴

The role that carers play may also come at a cost to their own health and wellbeing. For example, over half of people caring for people after stroke say they have felt depressed.⁶⁵

The worsening of mental and physical health of carers is a distressing experience for the carers themselves and for those they care for. It can lead to unplanned hospital stays for the carer and cared for individuals, and to a greater reliance on local health and social care services. It is therefore in the enlightened self interest of a health system struggling to keep up with demand to provide emotional and practical help to everyone who looks after a person with a long term condition.



Only two in ten stroke survivors report receiving information, advice and support on coping with the emotional aspects of stroke.⁶⁵

PRACTICAL NEEDS: THE FACTS



60%

60% of people who approach the Citizen's Advice bureau for debt advice are affected by mental illness.⁶⁶

30%

Only 30% of people using mental health services report being asked about any financial difficulties by their health and social care professional.⁶⁷

80%

Four in five people are affected financially by their cancer diagnosis. On average, people are £570 worse off per month.⁶⁸

EMOTIONAL AND PSYCHOLOGICAL NEEDS: THE FACTS



40%

More than two thirds of older carers report that their experience of caring has damaged their psychological wellbeing, and more than 40% say that their mental health has worsened in the past year.⁶⁹

<50%

Nearly half of cancer carers report that providing care impacts negatively on their mental health⁷⁰ and half report not receiving support of any kind.⁷¹

Coordinated care

People living with long term conditions and their families are often in contact with a number of different professionals and parts of the system. The more complex someone's needs, the more complicated this picture can get. Achieving properly coordinated care requires clearly defined responsibilities across all sectors and professional boundaries, supported by good communication and cooperation, with staff working to a set of common goals.

Unfortunately much of the care experienced by people living with long term conditions remains poorly coordinated, resulting in worse health outcomes, unnecessary distress and a waste of both time and resources.

Good care coordination should also be underpinned by a proper care plan supported, for more complex situations, by a dedicated care coordinator. A care coordinator works to organise care around the individual and acts as a point of contact for professionals, patients and their carers. These roles can be carried out by GPs, specialist or community nurses, and allied health professionals or indeed by non-health care staff such as support workers and dedicated service coordinators.

However, not enough people, even those with complex needs, have access to such coordinated support. Specialist nurses play a key role in coordinating care for patients, whilst also generating efficiencies, for example through reducing hospital admissions, prescribing errors and lengths of stay in hospital.^{72, 73} But, not enough people, even those with complex needs, have access to such coordination support.

- Only half of stroke services provide people with a single point of contact, often a specialist nurse.⁷⁴
- Around a third of hospitals don't have a diabetes specialist nurse working on their inpatient wards.⁷⁵
- Only around a fifth of people admitted to hospital with heart failure were seen by a specialist nurse, and less than two thirds were referred to a specialist nurse for follow up.⁷⁶



Nikki, 17, Surrey

“I was 14 when I started to hear voices and as a result I began to self-harm.

I tried to get help through school and my GP but wasn't put in touch with any mental health support. I tried to take my own life a number of times and had lots of trips to A&E, but they would turn me away. So I would head home, still having suicidal thoughts, and hurt myself again.

This continued for about six months until I was eventually put in touch with a mental health team and properly diagnosed. Unfortunately the support I was offered by the service was not enough and I ended up in a number of hospitals all over the country, often far away from family and friends. It was a different place each time and having to constantly start again, telling my story to new doctors and trying to build up trust, was really tough.

It took a year for me to finally be offered dialectical behavioural therapy (DBT) and that changed everything. I am now studying and have moved house. I just wish I had been offered much more joined up help earlier.”





33% of hospital patients said they had no information about danger signs to watch out for after discharge, and 24% had no information on who to contact if they experienced any problems.⁷⁷

A care plan helps to describe the responsibilities of different professionals involved in caring for a person, and how that care should be coordinated, on a daily basis and in times of crisis. The plan should be based on the personal priorities and goals of the individual and agreed in discussion with their health and care teams. Care planning is an important way to help make sure different services and professionals are all pulling in the same direction, to meet that person's needs. Yet despite the clear benefits of this approach, care plans are often not understood or used systematically. Only 12% of all people with a long term condition report knowing that they had a care plan.⁷⁸

It is still all too common for care coordination to break down when people move between services and settings. This is particularly likely when someone is discharged from hospital.

Older people frequently report uncertainty, and a lack of confidence and support after they have been discharged from hospital.⁷⁹ Distressing delays can also occur on the day of discharge itself, for example if transport, medicines and onward care are not sorted out. These delays can leave patients in a state of limbo: stuck at a halfway point between the hospital and their onward destination, unclear about who is responsible for them and their care.⁸⁰ In 2011/12 204,709 people aged over 75 were readmitted to hospital as an emergency within one month of discharge, 3,000 more than just the year before. Overall, £1.8 billion is spent on readmissions to hospital within 28 days of being discharged,⁸¹ of which a large proportion is due to other health issues,⁸² suggesting poor coordination of care plays a part.

COORDINATED CARE: THE FACTS



One in three

One in three people with diabetes do not get all the tests and investigations needed to help them prevent complications.⁸³



Nearly half of stroke survivors report that the failure of health and social care to work together has resulted in worse care for them.⁸⁴



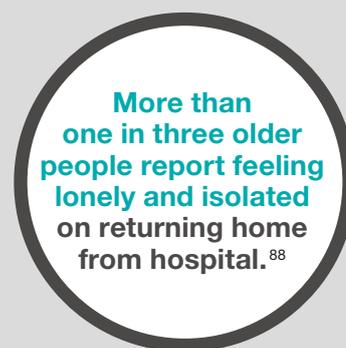
More than two thirds of people with neurological conditions report not having been offered a care plan.⁸⁵



Seven out of ten people seeking help from a doctor or nurse for their asthma in the last year did not have a written action plan.⁸⁶



25% of people with a diagnosis of schizophrenia report not having an agreed care plan.⁸⁷



More than 40% of breast cancer patients report not being given enough help and care from health and social services after leaving hospital.⁸⁹

Conclusion

This report does not try to analyse and present everything that goes on across our health and care services in England. We all know that a huge amount of commitment is demonstrated and excellent care is provided by the many doctors, nurses, care workers and carers working to support people with long term conditions.

But, as the data here shows, there is still a long way to go before we can confidently say that we are getting it right for every individual every time.

Over the next five years the NHS is embarking on delivering on its vision to be the best in the world, whilst reducing waste and costs. Action to ensure the millions of people living with long term conditions receive the care and support needed to stay well must be a top priority. This means:

- preventing ill health wherever possible;
- diagnosing conditions early and intervening quickly to prevent crisis and complications;
- helping people to be more in control of their own health and care;
- and joining up services around the person's needs, be they medical, emotional or practical.

The benefit of local decision-making is that services can be designed to meet the needs of local communities. However, this has to be backed with the right funding, incentives and regulation to ensure commissioners and providers can do the right thing for patients and are held to account for results they achieve. This will require strong local and national leadership and a clear strategy across Government and national bodies.

The Richmond Group of Charities has a lot of experience to contribute to realising these ambitions. We will continue to advocate for an approach that focuses on what matters to people and we will work to hold to account those responsible for delivering the changes we need. The test for whether things are working is whether stories like Norah's become more common, and whether the stories of people like Connie, Nick, Patricia and Nikki, who we heard from in this report, will be different in five years time.

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"At a time when the NHS risks becoming a political football ahead of the general election, this report focusses on what really matters – the patient experience. It shows that although there is much that is good in the NHS, fairly easy and common sense changes could transform so many lives. [Every politician ought to read this report before making speeches about the future of the NHS.](#)"

Jackie Ashley

"Too often NHS or social care is fragmented because it is organised around the priorities of different organisations rather than wrapped around the needs of the service user. [As this report shows, this not only destabilises people's lives, but it is also destabilising the sustainability of the NHS and social care.](#) It is right to argue that in the next five years this has got to change."

Paul Corrigan

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Vital signs

Taking the temperature of health and care services for people living with long term conditions.

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