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TRAFFORD
COUNCIL

# AGENDA PAPERS FOR

## HEALTH AND WELLBEING BOARD

**Date: Thursday, 6 June 2013**

**Time: 6.30 p.m.**

**Place: Committee Room 2 and 3, Trafford Town Hall, Talbot Road, Stretford M32 0TH**

| | **AGENDA**     **PART I** | **Pages** |
|---|---|---|
| 1. | **ATTENDANCES**<br>To note attendances, including officers, and any apologies for absence. | |
| 2. | **MINUTES**<br>To receive and if so determined, to approve as a correct record the Minutes of the meeting held on 11th April, 2013. | 1 - 4 |
| 3. | **NHS ENGLAND BUSINESS PLAN**<br>To receive a presentation and supporting report from Clare Yarwood, NHS England. | 5 - 30 |
| 4. | **TRAFFORD'S INTEGRATED CARE PLAN**<br>To receive a report and presentation from Gina Lawrence, Director of Commissioning and Operations, Trafford Clinical Commissioning Group. | To Follow |
| 5. | **JOINT HEALTH AND WELLBEING STRATEGY UPDATE**<br>To receive a report from Abdul Razzaq, Joint Director of Public Health. | To Follow |
| 6. | **HEALTH AND WELLBEING DEVELOPMENT UPDATE**<br>To receive a presentation from the Chairman, Councillor Dr. Barclay. | Verbal Report |

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7. **PROPOSED CHANGES TO HEALTH AND WELLBEING MEMBERSHIP** To Follow

To receive a report from the Chairman, Councillor Dr. Barclay.

8. **DELIVERY OF THE WINTERBOURNE REVIEW AND CONCORDAT** To Follow

To receive a report and presentation from Gina Lawrence, Director of Commissioning and Operations, Trafford Clinical Commissioning Group.

9. **FEELING OVERWHELMED: THE EMOTIONAL IMPACT OF STROKE** 31 - 90

To note the attached report from the Stroke Association.

10. **DATE AND TIME OF NEXT MEETING**

To note that the next meeting of the Board will be at 6.30 p.m. on Tuesday 6th August 2013 at Trafford Town Hall.

**THERESA GRANT**
Chief Executive

Membership of the Committee

Councillor Dr. K. Barclay (Chairman), Dr. N. Guest (Vice-Chairman), Councillor J. Baugh, Councillor Miss L. Blackburn, D. Brownlee, A. Day, G. Lawrence, A. Razzaq, Councillor M. Young and T. Atherton

Further Information
For help, advice and information about this meeting please contact:
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This agenda was issued on 28th May 2013 by the Legal and Democratic Services Section, Trafford Council, Trafford Town Hall, Talbot Road, Stretford M32 0TH.

# HEALTH AND WELLBEING BOARD

## 11 APRIL 2013

## PRESENT

Councillor Dr. K. Barclay (in the Chair)., Dr. N. Guest (Vice-Chairman), Councillor Mrs. J. Baugh, D. Brownlee, G. Lawrence, A. Razzaq and C. Yarwood

In attendance

| | |
|---|---|
| Wendy Thomas | Birch Thomas Associates |
| Terry Atherton | Independent Advisor to the NHS |
| Imran Khan | Partnerships Officer |
| Helen Mitchell | Democratic Services Officer |

## 1. ATTENDANCES

Apologies for absence were received from Councillor Miss L. Blackburn and Councillor M. Young.

## 2. MINUTES

The minutes of the Shadow Health and Wellbeing Board held on 15 January 2013 were agreed as a correct record.

## 3. HEALTH AND SOCIAL CARE IN GREATER MANCHESTER - AGMA EXECUTIVE BOARD PAPER

The Corporate Director for Children, Families and Wellbeing presented a report which detailed the Association of Greater Manchester Authorities' (AGMA) priorities for health and social care reform across the conurbation.

It was noted that the Council's Executive welcomed the priorities and that the Integrated Care Redesign Board (ICRB) would also consider the information detailed in the report.

RESOLVED:

(1) That the Board endorse the approach and recommendations outlined in the report and commit to working locally with partners to provide a local perspective and context to the proposals;

(2) That the Chairman of the Health and Wellbeing Board write to the AGMA lead officer confirming this commitment;

(3) That the letter from the Chairman be circulated to Board members or presented at the next meeting.

## 4. TRAFFORD CLINICAL COMMISSIONING GROUP UPDATE

The Chief Clinical Officer of Trafford CCG gave an oral update on the work of the organisation since the Board last met.

He advised that the CCG had received authorisation from the Department of Health and that colleagues were monitoring the performance of Commissioning Support Services to ensure value for money. It was noted that the Community Services procurement exercise had completed and that Pennine Care were the main provider in the Borough. Additionally, it was reported that work was progressing in relation to the ICRB.

Reference was also made to the referral by the Joint Scrutiny Committee to the Secretary of State for Health in relation to the New Health Deal for Trafford and that a dialogue with Strategic Programme Board members should be retained after the outcome was known.

In discussion, it was raised that future reports from the CCG should be included with the agenda papers for the Board.

RESOLVED –

(1) That the report be noted;

(2) That future reports from the CCG be circulated with agenda.

## 5. PUBLIC HEALTH TRANSITION UPDATE

The Director of Public Health presented an update on the transition of public health functions, assets, liabilities and staff from NHS Trafford to the Local Authority on 1 April 2013. The report detailed the successful nature of the transfer and the integration of public health within the wider organisation.

RESOLVED – That progress on the transfer of public health staff to Trafford Council on 1 April 2013 be noted.

## 6. JOINT HEALTH AND WELLBEING STRATEGY

The Board considered a report from the Director of Public Health which documented the progress in finalising the Joint Health and Wellbeing Strategy (JHWS). It was noted that the Strategy had been subject to an extensive period of consultation with relevant stakeholders and was to be launched at the Trafford Partnership conference in April 2013.

The Board discussed the launch at the Partnership Conference and were concerned that the necessary agreement of the Board, the Council's Executive and the CCG was required before any such launch took place. In response, it was noted that the launch would be informal and that the final agreement of the Strategy by the Board, the Council's Executive and the CCG would be made prior to its formal launch.

In order to support the delivery of the Strategy, the associated action plan was discussed and it was agreed to use the template which emphasised the ‘new things we plan to do’. As a result of this, the action plan was to be redrafted by the Joint Commissioning Managers Board and was to include a small number of key actions for each priority area. It was also agreed that it was important to direct resources to those priorities which would achieve the largest impact.

The Board considered the emotional health and wellbeing of young people and efforts were made to establish the commissioning responsibilities of NHS England, the CCG and the Local Authority. It was agreed that work to clarify responsibilities would be undertaken and that this information would be presented to Board members.

RESOLVED -

(1) That the progress on the preparation of the JHWS 2013-16 be noted;

(2) That the development of the JHWS action plans for the identified priority areas be noted;

(3) That the JHWS be agreed by the Health and Wellbeing Board and the CCG Board prior to its formal launch;

(4) That work to establish commissioning responsibilities in relation to the emotional health and wellbeing of children and young people be carried out and that this information be presented to Board members in the most appropriate way.

## 7. HEALTH WATCH UPDATE

The Board considered an update report relating on the progress of Healthwatch following its transition from Local Involvement Networks (LINks) on 1 April 2013.

It was noted that the Chairman of Trafford Healthwatch had been appointed and that the Board was in place albeit with a small number of vacancies. Any further appointments to the Board would be made by Healthwatch and not the Local Authority as the commissioner of the service. Additionally, the organisation would be based from Trafford Housing Trust’s offices in Sale.

RESOLVED – That the update be noted.

## 8. TRAFFORD PARTNERSHIP UPDATE AND LOCALITY WORKING

The Partnerships Officer provided an update to the Board on the work of the Trafford Partnership and locality working.

The Board were reminded of the outcomes of their away day in March and that a similar session was to be organised in May. This was to explore the issues relating to poverty and welfare reform and the attendance of representatives from the CCG were sought.

The Board were also informed that recruitment of Community Ambassadors to the Locality Boards had been completed and there was a good level of representation from those who had a keen interest in health and wellbeing issues. A training session on Locality Partnerships had been organised and representatives from the CCG had been sought.

With reference to the issue of welfare reform, it was raised that as part of Integrated Care, GP's would be able to confidently signpost patients to sources of welfare advice.

RESOLVED – That the update be noted.

## 9. GREATER MANCHESTER HEALTH AND WELLBEING BOARD

The Board received the minutes of the Greater Manchester Health and Wellbeing Board held on 15 February 2013. It was suggested that there was an apparent disconnect between the work of the Board at Greater Manchester level and the work undertaken locally. Furthermore, it was raised that improvements could be made to the style of the meetings to ensure they are conducive to effective discussion.

RESOLVED – That the minutes of the Greater Manchester Health and Wellbeing Board held on 15 February 2013 be noted.

## 10. KEY MESSAGES

The Chairman of the Board summarised the key themes from the meeting as follows:

(1) That work be progressed to ensure the JHWS is completed and that necessary agreements on its content are finalised by the Board and the CCG prior to its formal launch;

(2) That the Chairman of the Board writes to AGMA to endorse the approach taken in relation to health and social care reform in Greater Manchester.

## 11. DATE AND TIME OF NEXT MEETING

The next meeting of the Health and Wellbeing Board is to be held in Committee Rooms 2 and 3 at Trafford Town Hall on 6 June 2013, 6.30pm.

The meeting commenced at 1.20 pm and finished at 2.00 pm

**TRAFFORD COUNCIL**

**Report to:** **Health and Wellbeing Board**
**Date:** **Thursday 6th June 2013**
**Report for:** **Discussion**
**Report of:** **Claire Yarwood –NHS England**

## Report Title

Putting Patients First – NHS England Priorities for 2013-14 & 2014-15

## Summary

This report provides detail of NHS England's operating model, explaining how the mandate from the government will be delivered and how outcomes for people will be improved. It clarifies within that the specific objectives and ambitions to be delivered through the Greater Manchester Area Team.

NHS England has set out an 11-point scorecard reflecting core priorities, against which we will measure our performance and within which two measures take precedence – firstly, direct feedback from patients and their families and secondly getting direct feedback from NHS staff.

## Recommendation(s)

The Health & Wellbeing Board is invited to consider the priorities of NHS England (formally the National Commissioning Board) through the Local Area Team to understand how these priorities might best support the aims of the board and the Joint Health and Wellbeing Strategy.

Contact person for access to background papers and further information:

Name: Imran Khan
Extension: 0161 912 1361

# 1.0 Background

*A New Health & Social Care System for England*

The new health and care system became fully operational from 1 April to deliver the ambitions set out in the Health and Social Care Act. NHS England, Public Health England, the NHS Trust Development Authority and Health Education England will take on their full range of responsibilities.

Locally, clinical commissioning groups – made up of doctors, nurses and other professionals – will buy services for patients, while local councils formally take on their new roles in promoting public health. Health and wellbeing boards will bring together local organisations to work in partnership and Healthwatch will provide a powerful voice for patients and local communities.

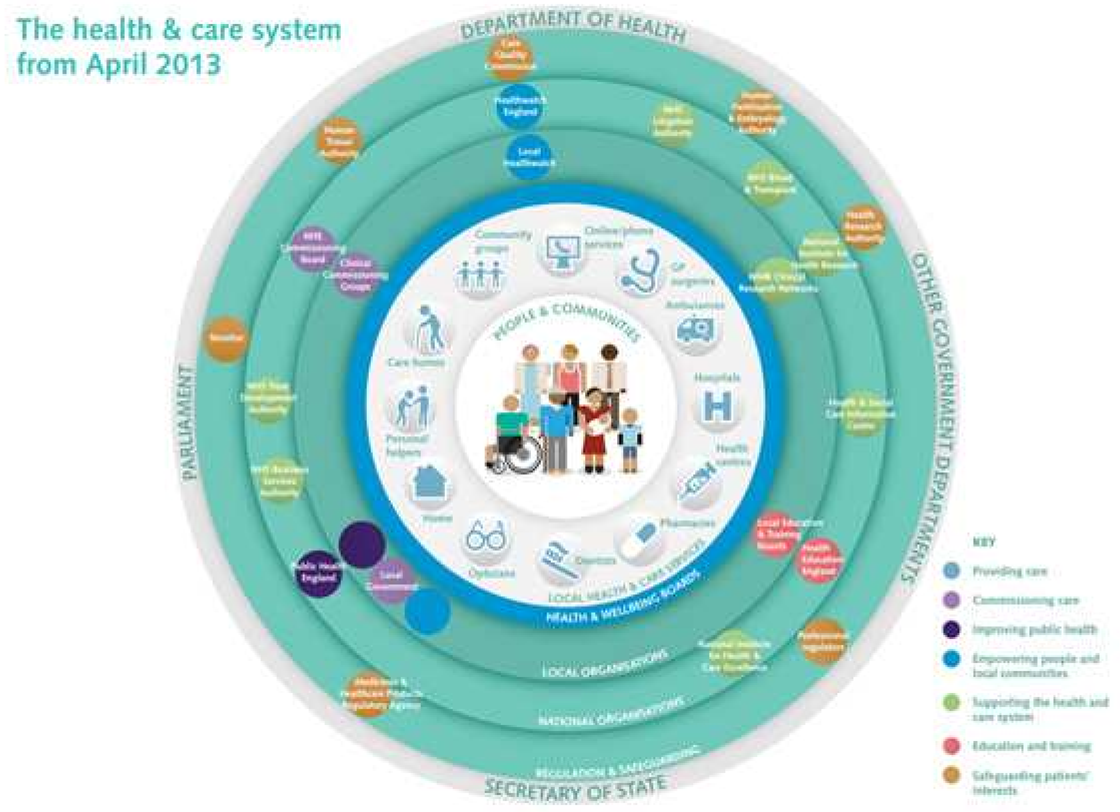
These changes will have an effect on who makes decisions about NHS services, how these services are commissioned, and the way money is spent.

Some organisations such as primary care trusts (PCTs) and strategic health authorities (SHAs) have been abolished, and other new organisations such as clinical commissioning groups (CCGs have taken their place.

A new regulator, Monitor is established to protect and promote the interests of NHS service users. The NHS Trust Development Authority will support the work to ensure that the vast majority of hospitals and other NHS Trusts will become foundation trusts by 2014.

In addition, local authorities will take on a bigger role, assuming responsibility for budgets for public health. Health and wellbeing boards will have duties to encourage integrated working between commissioners of services across health, social care, public health and children's services involving democratically elected representatives of local people. Local authorities are expected to work more closely with other health and care providers, community groups and agencies, using their knowledge of local communities to tackle challenges such as smoking, alcohol and drug misuse and obesity.

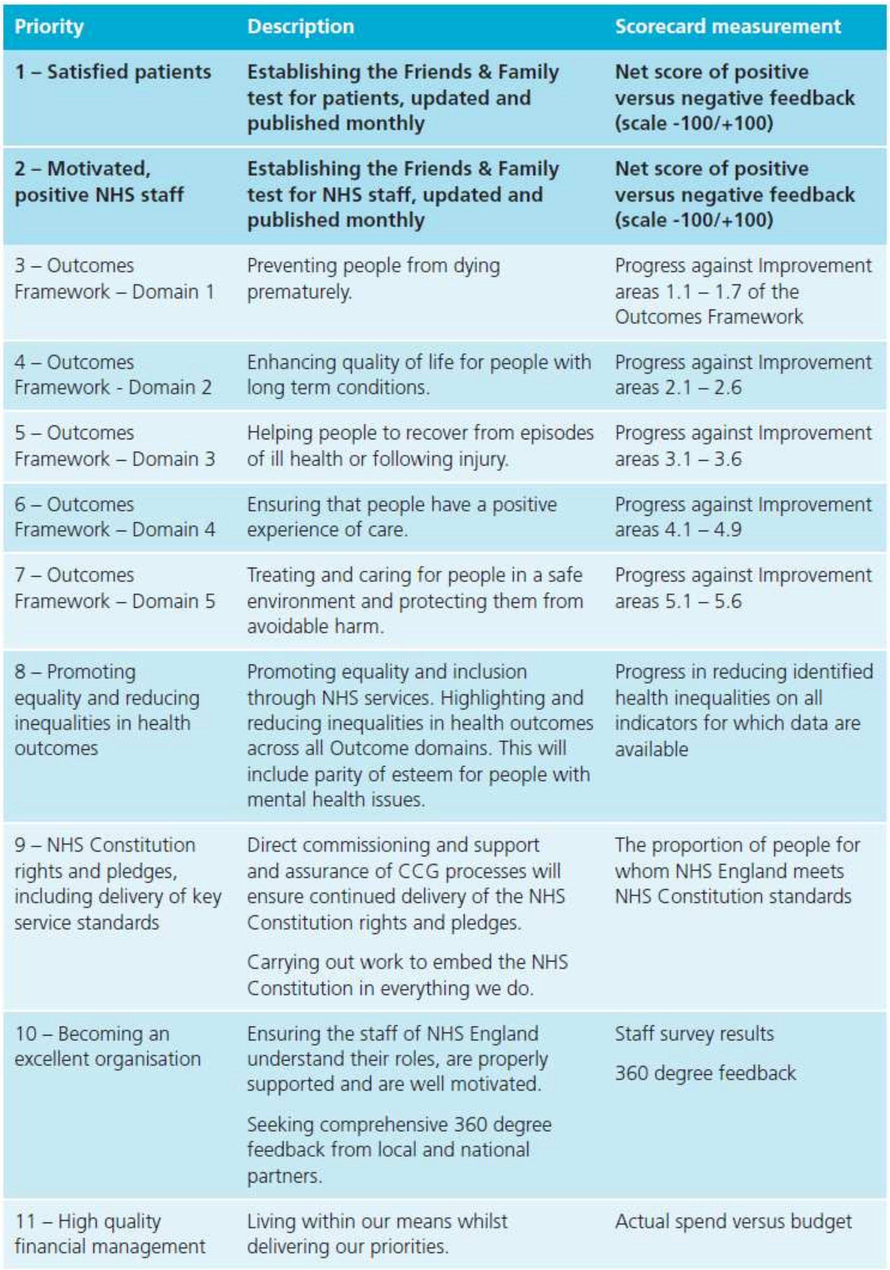
However, none of these changes will affect how people access NHS services in England. The way patients book a GP appointment, get a prescription, or are referred to a specialist will not change. Healthcare will remain free at the point of use, funded from taxation, and based on need and not the ability to pay.



*Purpose of the Report*

1.1 This report provides detail of NHS England’s operating model, explaining how the mandate from the government will be delivered and how outcomes for people will be improved. It clarifies within that the specific objectives and ambitions to be delivered through the Greater Manchester Area Team.

1.2 The year 2013/14 is a critical one for the NHS. The only acceptable legacy of the Francis report is that the NHS changes as a result of its findings. The Department of Health has published the response to the Francis report, and we will play our full part in delivering the actions described in it. We will put patient care at the centre of all we do through our focus on patient satisfaction and outcomes. The healthcare system is also facing the challenge of significant and enduring financial pressures. People’s need for services will continue to grow faster than funding, meaning that we have to innovate and transform the way we deliver high quality services within the resources available. In underpinning the move to a new system, where quality is at the heart of everything we do, we have a set of clear core priorities. We will measure progress against these to produce an 11-point NHS England Scorecard:



| Priority | Description | Scorecard measurement |
|---|---|---|
| **1 – Satisfied patients** | **Establishing the Friends & Family test for patients, updated and published monthly** | **Net score of positive versus negative feedback (scale -100/+100)** |
| **2 – Motivated, positive NHS staff** | **Establishing the Friends & Family test for NHS staff, updated and published monthly** | **Net score of positive versus negative feedback (scale -100/+100)** |
| 3 – Outcomes Framework – Domain 1 | Preventing people from dying prematurely. | Progress against Improvement areas 1.1 – 1.7 of the Outcomes Framework |
| 4 – Outcomes Framework - Domain 2 | Enhancing quality of life for people with long term conditions. | Progress against Improvement areas 2.1 – 2.6 |
| 5 – Outcomes Framework – Domain 3 | Helping people to recover from episodes of ill health or following injury. | Progress against Improvement areas 3.1 – 3.6 |
| 6 – Outcomes Framework – Domain 4 | Ensuring that people have a positive experience of care. | Progress against Improvement areas 4.1 – 4.9 |
| 7 – Outcomes Framework – Domain 5 | Treating and caring for people in a safe environment and protecting them from avoidable harm. | Progress against Improvement areas 5.1 – 5.6 |
| 8 – Promoting equality and reducing inequalities in health outcomes | Promoting equality and inclusion through NHS services. Highlighting and reducing inequalities in health outcomes across all Outcome domains. This will include parity of esteem for people with mental health issues. | Progress in reducing identified health inequalities on all indicators for which data are available |
| 9 – NHS Constitution rights and pledges, including delivery of key service standards | Direct commissioning and support and assurance of CCG processes will ensure continued delivery of the NHS Constitution rights and pledges.<br>Carrying out work to embed the NHS Constitution in everything we do. | The proportion of people for whom NHS England meets NHS Constitution standards |
| 10 – Becoming an excellent organisation | Ensuring the staff of NHS England understand their roles, are properly supported and are well motivated.<br>Seeking comprehensive 360 degree feedback from local and national partners. | Staff survey results<br>360 degree feedback |
| 11 – High quality financial management | Living within our means whilst delivering our priorities. | Actual spend versus budget |

## 2.0 NHS England Eight Key Activities

2.1 Having set out the 11 scorecard priorities by which people can judge our overall progress, this section explains the means through which NHS England will go about achieving them. NHS England does of course have a more detailed set of requirements with this government set out in its Mandate. These are captured in Annex 2 of the business plan as part of our public accountability. NHS England will deliver better outcomes for patients in eight ways:

- Supporting, developing and assuring the commissioning system;
- Direct commissioning;
- Emergency preparedness;
- Partnership for quality;
- Strategy, research and innovation for outcomes and growth;
- Clinical and professional leadership;
- World class customer service: information, transparency and participation; and
- Developing commissioning support.

2.2 Through these eight core work areas we will lead the commissioning system in shaping the climate for success. We will deliver on the ground as commissioners ourselves and we will help develop the entire commissioning system to be in the best possible position to make a difference to the people of England. Through matrix working, every member of staff working for NHS England will be contributing to at least one of these areas in their roles.

2.3 The Area Team will be the local representation of NHS England in delivering the 11 priorities through the eight components of the Operating Model.

### 2.3 Supporting, developing and assuring the commissioning system

2.3.1 High quality, clinically-led commissioning will be a mainstay of the new healthcare system. Commissioning will focus on issues that matter locally, underpinned by robust public and patient involvement. We will stand alongside CCGs as commissioners of healthcare services, and provide the leadership and support to help them to become excellent commissioners.

2.3.2 CCGs are new organisations and we will continue to support their development as they move through authorisation and beyond. The authorisation process provided an assessment of how each CCG is developing against a set of core commissioning competencies, with Greater Manchester's CCGs performing strongly throughout this process. The results of this will shape the support and development we provide for CCGs. During 2013/14 we will:

- Identify development needs for all CCGs, and establish development programmes from support organisations;
- Establish a maturity model for CCGs, and assessment criteria to monitor progress;
- Establish network arrangements to meet CCG needs for adoption and spread of best practice;
- Establish a programme for collaborative commissioning between CCGs with area teams, local authorities and Public Health England; and
- Support CCGs to deliver the plans that they have developed with local communities.

**Greater Manchester Area Team Key Priority 1**

*Supporting Excellent Clinical Commissioning Groups*

2.3.3 The Area Team is clear that one of the principal markers of its success is the degree to which Greater Manchester benefits from 12 highly successful autonomous CCGs. Our shared ambitions in relation to improvements in each of the domains of the NHS

Outcomes Framework, our intentions to uphold the NHS Constitutional rights of Greater Manchester's communities and the maintenance of stable and sustainable health and care services will primarily be delivered through the endeavours of the CCGs. Our relationship with CCGs will be one which prioritises and supports improvements in commissioning capability and acknowledges those areas where we stand side by side as co-commissioners with local authorities and other partners.

**Greater Manchester Area Team Key Priority 2**

2.3.4 As a direct commissioner of services, the Area Team will work in partnership with CCGs and other local commissioners to ensure alignment and integration of their strategy. In carrying out this support and assurance role, we will establish mutual accountability between ourselves and local commissioners, and we will measure our success by the way that we are able to support CCGs to achieve their objectives. Through NHS clinical commissioners, we will seek and publish 360 degree feedback from CCGs and other key stakeholders on how we are promoting autonomy in local organisations, and how effectively NHS England is building relationships.

### *Choice & Competition*

2.3.5 Choice and competition can be an important lever for commissioners to improve the quality and efficiency of services. Choice can help ensure people get services that best meet their needs, and competition can be an important lever for driving up quality and innovation. Competition is not an end in itself and will only be used as a means of improving outcomes. At the national level we are working in partnership with Monitor, the independent regulator of NHS foundation trusts, and with CCG and provider representatives to develop a Choice and Competition Framework. The Framework will offer practical tools, guidance and evidence so that commissioners and providers are able to deliver improved outcomes for people through more effective use of choice and competition.

### *Resources Tools & Guidance*

2.3.6 During 2013/14 NHS England will work with the Commissioning Assembly and other key stakeholders to design the standard contract. The contract will be issued alongside our planning guidance in December 2013, ready for commissioners to use in the 2014/15 financial year. We have established the Quality Premium for 2013/14. The Area Team will continue to work with CCGs and other partners, including local clinicians and patients, to ensure that the Quality Premium for 2014/15 continues to reward improvements in quality, outcomes and inequalities in a range of national and local measures. In 2014/15 the quality premium will include a measure for mental health outcomes.

| Key deliverables: supporting, developing and assuring the commissioning system | Timelines |
|---|---|
| 80% of outcomes improvements identified in CCG plans delivered | April 2014 |
| Overall positive CCG satisfaction with NHS England development support | Annual survey |
| Choice and competition framework (and supporting documents) published | July 2013 |
| Overall positive CCG satisfaction with resources, tools and guidance provided by NHS England | Annual survey |

## 2.4 Direct commissioning

2.4.1 NHS England is responsible for directly commissioning £25.4bn of healthcare services including primary care, specialised services, secondary care dental services, some public health services, offender health and armed forces health. These services will be commissioned by the 27 area teams of NHS England.

2.4.2 Much of our early focus will be on embedding a number of single operating models for how we will carry out our direct commissioning responsibilities. These operating models will seek to address inequalities in access and outcomes, to take account of unmet need for access to high quality services right across the country and to allow us quickly to apply learning and best practice to different geographical areas. At the same time, we will focus on patient safety, giving clear guidance on how to commission a safer service, manage serious incidents and use safety reviews to support commissioning for improvement.

2.4.3 Where services we commission directly need to join up with locally commissioned services, the Area Team will co-ordinate with CCGs and other partners, to ensure people experience a seamless and integrated service.

*Primary care*

2.4.4 Primary care has a key role to play in improving health outcomes and reducing health inequalities. We know that good primary care has a positive impact across the whole of the health and social care system. Evidence shows that strong and effective primary care services are vital for health economies and for delivering high quality, best value health services and healthy populations.

2.4.5 As a single commissioner of primary care services, we have the unique opportunity to redefine the role of primary care in an effective healthcare system and to take steps to address inequalities of access to primary care services, whilst improving the quality of care and outcomes for patients across the country. We aim to do this by:

- Developing and reviewing contract levers to ensure that maximum benefits are achieved through rewarding quality services and better outcomes for patients;

- Managing the smooth transition from Primary Care Trust (PCT) commissioning to NHS CB area teams. The single operating model we will develop will include developing a single approach for effective performance management of primary care;
- Improving the skills of practitioners in primary care through the development of robust workforce planning;
- Developing and maintaining mechanisms to enable revalidation of GPs, ensuring that skills are up to date and clinical standards remain high; and
- Timely, equitable access to primary care services in and out of hours.

2.4.6 Some patients find it more convenient to access GP services away from home. We will evaluate the results of the GP choice pilots and consider how we can apply successes more widely. We will move towards a more equitable system of GP practice funding to support patient choice. We will continue to support and incentivise practices to offer greater access to services through digital means.

**Greater Manchester Area Team Key Priority 3**

*Primary Care and Healthier Together*

2.4.7 The Area Team in Greater Manchester is ensuring its direct commissioning responsibilities are undertaken and developed in line with our wider ambitions through the Healthier Together programme of health and care reform for Greater Manchester. To support the development of integrated care strategies and delivery plans across Greater Manchester, work is ongoing to develop further the vision for Primary Care which includes General Practice, Dental, Pharmacy and Optometry. To support this process, the characteristics of a high performing, high quality primary care system have been identified, along with some of the desired outcomes and potential ideas for how these could be achieved.

2.4.8 The developmental objectives for Primary Care are as follows:

- Support the delivery of enhanced integrated care across Greater Manchester to deliver improved outcomes for the whole population
- The systematic and proactive management of chronic disease as a tool to improve health outcomes, reduce inappropriate use of hospitals and positively impact on health inequalities
- Ensuring a focus on key patient groups, including 0-5s, Frail Elderly and those nearing the end of life
- Reduce unnecessary hospital attendances and admissions
- Engagement and empowerment of patients
- Population-based approach to commissioning - directing resources to the patients with greatest need and redressing the ‘inverse care law’ by which those who need the most care often receive the least.

2.4.9 The table below provides a draft suite of characteristics of a high performing primary care system, together with thematic areas for outcomes . Once the review process is completed and the characteristics are agreed, more definitive work will be done to develop the outcome metrics. The characteristics have been split into themes, i.e. what we are seeking to achieve and enablers, ie the means by which we will secure achievement.

| **Themes** | **Potential Outcomes** |
|---|---|
| Patients are involved in the design of the primary care system and as partners in the management of their own conditions and health needs | Improved Health Outcomes<br>Improved Patient Experience<br>Reduction in hospital admissions |
| Integration between primary, social and community care forming part of an overall approach to pathway based commissioning | Reduced admissions to secondary care<br>Reduced hospital lengths of stay<br>Reduced readmissions to hospital<br>Increased measures of patient independence |
| Long term conditions are effectively managed in primary care with interfaces with secondary care clearly defined and managed | Improved health outcomes<br>Reduced admissions to hospital leading to improved patient experience<br>Reduction in cost |
| A systematic approach to primary prevention is implemented, eg with regard to alcohol, smoking, exercise | Reduction in numbers of smokers and problem drinkers, reducing costs and improving health<br>A healthier population, more able to play a full role in society |
| Secondary prevention interventions are defined and in place, eg via the effective use of disease registers, taking measures to reduce high blood pressure, prescription of statins | Improved life expectancy, reduced complications<br>Reduced costs over the medium term |
| Effective management of those patients with mental health needs | Improved patient experience<br>Improved health outcomes<br>Reduced costs |
| Effective arrangements for primary care management of end of life care | Improved patient and carer experience<br>Potential to improve quality of care<br>Improved ability to respond to patient preferences |
| Effective medicines management | Improvements in the quality and safety of prescribing<br>Improved patient experience and health outcomes<br>Reduced costs |
| Managing elective and urgent care activity | Improved outcomes, (where late referral issues are addressed)<br>Reduction in unnecessary hospital attendances and admissions<br>Improved quality of clinical care |

| | |
|---|---|
| | Improved patient experience<br>Improved cost effectiveness |

2.4.10 The Healthier Together Strategic Direction Case sets out a 10 point plan for the development of primary care which is reproduced below:

i. Clear primary care commissioning plan for 2013/14.

ii. Review of primary care “discretionary” spend to ensure maximum health gain for the population and appropriate system incentivisation.

iii. Transfer of resource from secondary to primary care to deliver enhanced management of long term conditions. This may require initial pump priming to ensure accelerated pace of change.

iv. Explore opportunities for increased working across practices.

v. Provision of support for GPs to help improve health literacy of the population and increase prevention.

vi. Investment in local technological solutions to improve sharing information between care professionals as well as enable patients to access their own records.

vii. Development of clear patient pathways and access points across Greater Manchester.

viii. Additional support where required for CCGs to plan and implement effective integrated care strategies for their local population.

ix. Implement a standardised enhanced role for primary care nursing and create an investment programme to maximize the currently varied and underutilised workforce.

x. Support to increase the amount of training placements for GPs across Greater Manchester.

**Specialised services**

2.4.11 Specialised services are those services, often provided in relatively few hospitals, accessed by comparatively small numbers of patients, but with catchment populations of more than one million. These services tend to be located in specialist hospital trusts that can recruit staff with the appropriate expertise and enable them to develop their skills. Examples include long-term conditions such as renal dialysis, complex interventions such as liver transplants, rare cancers and secure forensic services.

**Greater Manchester Area Team Key Priority 4**

*Greater Manchester’s Specialised Services*

2.4.12 the Area Team will support the creation of a consistent, robust and evidence-based approach to the way these services are commissioned across the country, regardless of where the services are provided. Nationally NHS England will also establish a specialised services innovation fund to support innovative practice locally. The move to a more consistent approach to specialist service delivery will clearly identify those providers which are operating outwith the standards defined in the national specifications. This will provide important information relating to the configuration of specialist and related or dependent services and it will be important for Greater Manchester to support a clear alignment with the acute service priorities of the Healthier Together programme.

2.4.13 National service-specific clinical reference groups have supported the development of five national programmes of care through wide and expert engagement across clinical and patient stakeholders. Improved patient outcomes will be delivered through quality standards incorporated into the new contracts.

2.4.14 NHS England will develop outcome measures for all specialised services in line with the Outcomes Framework. This will build on previous work to develop and implement outcome measures, for example, the current measures of survival rates in rare cancers, survival post-transplant in transplant services and the percentage of patients with severe intestinal failure who are discharged home without any need for tube feeding, and the percentage patients with psychosis who can be discharged back to primary care after NICE recommended treatment.

2.4.15 The Cheshire Wirral and Warrington Area Team acts as the lead commissioner for specialised services for the North West. The Greater Manchester Area Team is working across the NW to establish appropriate governance arrangements, which must include engagement with CCGs to ensure a full pathway, total provider approach is taken in relation to the oversight of specialist services.

**Public health**

2.4.15 Public health is about helping people to stay healthy, changing lifestyle behaviours and preventing disease. Campaigns and interventions are used to promote healthy choices, while disease prevention helps people to avoid getting ill and enables early diagnosis through screening. Public Health encompasses a wide range of services such as immunisation, nutrition, tobacco and alcohol, drugs recovery, sexual health, pregnancy and children's health.

2.4.16 In the main, these services will be commissioned by Public Health England (PHE). NHS England at both national and Area Team levels will work in partnership with PHE so that we mutually support our common goals of improving health outcomes and promoting equality of access. The NHS Act 2006, Section 7a, sets out the important role we have in relation to the commissioning of screening and immunisation services, health intervention services for children aged 0-5 years and sexual assault services.

2.4.17 The 0-5 years programme in particular demonstrates the value of delivering public health programmes in partnership with other statutory agencies that have a responsibility and budget, in this case for the commissioning of children's services. The programme will strengthen the co-ordination of the link between needs assessment and strategy and provide a clear line of sight from the commissioning process through to the delivery of services. The 0-5 years programme includes the continued expansion of numbers of health visitors and family nurse practitioners (FNPs).

2.4.18 Screening programmes will be extended during 2013/14 for bowel cancer, breast screening and Human Papilloma Virus triage in cervical screening. New vaccines will be introduced for rotavirus in infants and for shingles in the elderly, reducing the incidence of painful and unpleasant conditions for sufferers whilst simultaneously reducing the burden on urgent care services.

**Greater Manchester Area Team Key Priority 5**

*Public Health Partnerships*

The Area Team will secure positive partnerships with local government partners and Public Health England to develop and deliver against our highest ambitions for public health improvement. This will prioritise improvements in screening and immunisation rates and address areas of variation in both offer and uptake.

### Dental health

2.4.19 NHS England will be responsible for commissioning all NHS dental care; across the hospital (secondary), community (e.g. care for people with special needs), and primary dental care settings, and managing some 10,000 contracts with 'high-street' dental practices. Our aim is to deliver excellence in commissioning NHS dental services including improvements in quality and patient satisfaction, and reductions in inequalities of access and outcomes.

### Offender health

2.4.20 With commissioning of offender health services, NHS England will be responsible for planning, securing and monitoring an agreed set of services for prisons, young offenders Institutions (YOIs), immigration removal centres, secure training centres, police custody suites, court liaison and diversion services and sexual assault services. In 2013/14, our focus will be to align the justice commissioning intentions with those of the NHS England offender teams and local partnerships, particularly for children and young people.

### Armed forces health

2.4.21 NHS England will focus on developing core requirements in new contracts and delivering on a number of commitments such as increasing and improving access to mental health services for serving personnel and veterans, as well as improving prosthetic care for veterans.

| Key deliverables: Direct commissioning | Timelines |
|---|---|
| All area teams will have contracts in place with providers that reflect the requirements of the single operating model for specialised services | June 2013 |
| 80% of all commissioning intentions implemented in full | April 2014 |
| All area teams will implement primary care quality assurance for all four contractor services | From April 2013 |

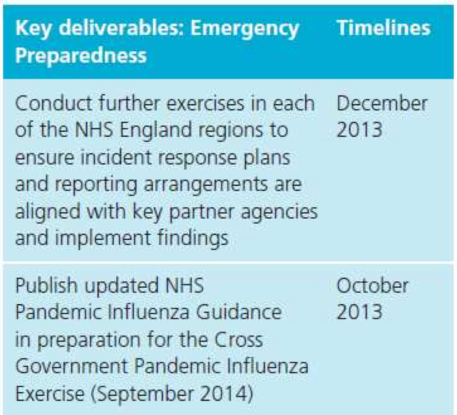
## 2.5 Emergency preparedness

2.5.1 The NHS needs to be able to plan for, and respond to, a wide range of incidents and emergencies that could have an impact on health or patient care. These incidents could be anything from extreme weather conditions to an outbreak of an infectious disease or a major transport accident. They often require a co-ordinated response at national and local level. The development of the capability and capacity to provide this response is a central element of NHS England’s role in safeguarding the public.

### Greater Manchester Area Team Key Priority 6

*Local Health Resilience Partnership*

2.5.2 In 2013/14, NHS England will implement new arrangements for effectively handling these incidents and emergencies, ensuring safe transition from existing organisations. In support of these arrangements the Area Team will lead, along with the nominated lead Director of Public Health, the Greater Manchester Local Health Resilience Partnerships (LHRP). The LHRP, which brings together the Area Team with other local partners, will provide on-going surveillance and a co-ordinated multi-agency response, where necessary.



| Key deliverables: Emergency Preparedness | Timelines |
|---|---|
| Conduct further exercises in each of the NHS England regions to ensure incident response plans and reporting arrangements are aligned with key partner agencies and implement findings | December 2013 |
| Publish updated NHS Pandemic Influenza Guidance in preparation for the Cross Government Pandemic Influenza Exercise (September 2014) | October 2013 |

## 2.6 Partnership for quality

2.6.1 Improvements in health and care are linked and the NHS and its public, private and voluntary sector partners can only provide the best and most effective service for patients and public when we work together to achieve their objectives.

*Francis and Winterbourne View reports*

2.6.2 The Francis and Winterbourne View reports described major failings in the delivery of care. In December 2012 the Department of Health published *"Transforming Care: A national response to Winterbourne View Hospital"*. The report laid out clear, timetabled actions for health and local authority commissioners working together to transform care and provide support for people with learning disabilities or autism who also have mental health conditions or behaviours viewed as challenging. The report outlined our shared objective to see the health and care system get to grips with past failings by listening to this very vulnerable group of people and their families, meeting their needs, and working together to commission the range of services and support which will enable them to lead safe and fulfilling lives in their communities.

2.6.3 The Francis report on events at the Mid Staffordshire Foundation Trust made 290 recommendations, but its single, overarching theme is clear: that a fundamental culture change is needed in the NHS to put people first. Robert Francis highlighted five themes when he presented his report. These were:

- A structure of fundamental standards and measures of compliance
- Openness, transparency and candour throughout the system underpinned by statute
- Improved support for caring, compassionate, and considerate nursing
- Stronger healthcare leadership
- Accurate, useful and relevant information

**Greater Manchester Area Team Key Priority 7**

*Quality Surveillance Groups and the National Quality Board*

2.6.4 In 2013/14, the Area Team will work with partners to develop our Quality Surveillance Group. We will review all of the existing agreements, in the light of organisational developments and, following the recommendations of the Francis report, we will ensure that we remain focused on the right priorities. We will support board to board meetings to set the strategic direction for these relationships.

**Greater Manchester Area Team Key Priority 8**

*Safeguarding*

2.6.5 The accountability and assurance framework sets out clearly the responsibilities of each of the key players for safeguarding in the future NHS. The framework has been developed in partnership with colleagues from the Department of Health (DH), the Department for Education (DfE) and the wider NHS and social care system. The Area Team Director of Nursing is responsible for supporting and providing assurance on the safeguarding of children and adults at risk of abuse or neglect.

2.6.6 The Area Team will work with CCGs to support them to fulfil and excel in their safeguarding role. We will implement the national safeguarding IT infrastructure and mobilise the professional support required to realise the benefits.

*Partnership working*

2.6.7 NHS England will work alongside other organisations at national and local level to achieve our goals of improving outcomes and reducing inequalities, meeting the requirements of the Mandate and achieving our financial obligations and statutory duties. This includes working alongside partners to jointly commission integrated health and social care packages for people.

2.6.8 NHS England developed a concordat with the Local Government Association (LGA). because of the unique nature of the relationship between health and local government. The local dimension of this partnership will be particularly important and will build on the relationship developed between AGMA and the PCT Cluster to ensure there is no interruption to either the focus or pace of our ambitions around public service reform. We will continue to work closely with AGMA and through the Greater Manchester and the local health and wellbeing boards to ensure joined up commissioning and services. The three priorities are:

§ Facilitating shared system leadership through Health and Wellbeing Boards;

§ Supporting local mechanisms for joint planning of services ;

§ Creating sector led improvement, public service reform and innovation.

2.6.9 NHS England has a shared interest in improving outcomes with national organisations, including the National Institute for Health & Clinical Excellence (NICE), the Care Quality Commission (CQC), the NHS Trust Development Agency (NTDA), Monitor, Health Education England (HEE), and Public Health England (PHE). We have partnership agreements with each of these organisations that will formalise the way we work with them on shared priorities and objectives.

*Integrated care and support*

2.6.10 Care is at its best when it is centred round the needs, convenience and choices of people and their families and carers. Many individuals have multiple needs, and these often span organisational boundaries. Their experience should be of care and support services that are as seamless as possible.

**Greater Manchester Area Team Key Priority 9**

2.6.11 Through Health and Wellbeing Boards, we will work with local commissioning partners to develop plans for integrated care in line with the requirements set out in *Everyone Counts* and implement plans for integration in each health and wellbeing area by April 2014.

2.6.12 As a system leader we are tasked in our Mandate from the government to promote integration and seek to remove barriers to it. NHS England is developing with partners a Common Purpose Framework, which will be published in May 2013. This will set out how we will promote, enable and encourage better integrated care and support across health and social care, including primary and secondary care, mental and physical health, and adult and children's services. Our aim is for person-centred and co-ordinated care and support to become the norm for everyone. In Greater Manchester we would recognise the work taking place through the Healthier Together programme and the priority afforded by NHS Trusts, CCGs and local authorities to a significant scale of ambition around integrated care positions us at the vanguard of national work on health & social care reform. The Area Team is keen, therefore, for Greater Manchester to respond to Ministers' proposals to identify 'pioneers' from examples of integrated care across the country, with the, with the emphasis on identifying and spreading learning for wider, rapid adoption.

**Greater Manchester Area Team Key Priority 10**

*Health & Social Care Reform in Greater Manchester*

2.6.13 The Healthier Together programme is part of a wider review of Health and Social care and public service reform in Greater Manchester aimed at saving and improving thousands of lives every year. Our vision is "For Greater Manchester to have the best health and care in the country". The programme will be led by the Greater Manchester CCGs acting together in the context of the ambitions they share with each other and with local partners. The Area Team is fully committed to supporting this programme on behalf of NHS England, as a member of each of the local Health & Wellbeing Boards and as a co-commissioner.

2.6.14 Such leadership requires a recognition that the future health and social care system will look substantially different and that improved quality of health care for Greater Manchester residents will underpin the following key principles of a new system:

- People can expect services to support them to retain their independence and be in control of their lives, recognising the importance of family and community in supporting health and well being;
- People should expect improved access to GP and other primary care services
- Where people need services provided in their home by a number of different agencies they should expect them to planned and delivered in a more joined up way.
- When people need hospital services they should expect to receive outcomes delivered in accordance with best practice standards with quality and safety paramount – the right staff, doing the right things, at the right time.
- Where possible we will bring more services closer to home (for example there are models of Christie led Cancer services delivered from local hospitals)
- For a relatively small number of patients (for example those requiring specialist surgery) better outcomes depend on having a smaller number of bigger services.
- Planning such services will take account of the sustainable transport needs of patients and carers.

- This may change what services are provided in some local hospitals, but no hospital sites will close.

2.6.15 This is a complex ambition. It requires the positive confluence of a number of potentially separate programmes of work;

- Local Authorities working with CCGs, Hospitals and the NHS England to develop models of integrated health and social care
- The work of CCGs and the NHS England in improving the consistency, reliability and accessibility of primary care services
- The work of local acute trusts to develop new models of out of hospital care – consultant geriatricians working as part of local teams for example
- The outcome of a clinically led redesign of some hospital services best planned on a GM footprint for reasons of clinical critical mass, in order to drive further improvement in outcomes from acute care.

2.6.16 Currently there are good models of integrated care in place in many parts of Greater Manchester, but rarely are they at the scale required to effect a significant transfer of resource into prevention of avoidable admissions to hospital and other care institutions. New models of contracting and reimbursement are required, to deliver models targeting not 1% or 5% but at least 20% of the cohort of the risk stratified population. New models of integrated care seeking to reduce avoidable admissions to hospitals and other care institutions will contribute to a changing role for local hospitals. Hospitals are crucially important partners in seeking to develop these new models and most recognise their quality and financial interest in seeing these new models of 'out of hospital care' develop.

2.6.17 Each local authority is working with partners to develop their Local Implementation Plan for integrated care by summer 2013. The Area Team will certainly work with all localities to ensure its direct commissioning responsibilities support an effective alignment with the Health & Wellbeing Board ambitions.

| Key deliverables: partnership for quality | Timelines |
|---|---|
| Delivery of 100% of actions set out in the Winterbourne View concordat and Francis response | June 2014 |
| Integrated care proposals implemented in every health and wellbeing board Area | By April 2014 |
| Quality Surveillance Groups operational in every region and area team | From April 2013 |
| Ensure that there is a capable system of safeguarding that is resilient to the transition and linked to quality assurance | From April 2013 |

## 2.7 Strategy, research and innovation for outcomes and growth

2.7.1 In order to deliver our core objectives, it is essential that we develop a strategy for sustained, long-term, service improvement to ensure that the NHS continues to deliver for everyone, whatever their background, against the backdrop of low financial growth and rising demand for healthcare service. We will place much greater emphasis on innovation in healthcare by providing the space and support for local systems to adopt innovative practice. The key elements to our approach in 2013/14 will be:

- *A ten year strategy for the NHS* – NHS England will lead a national and local debate with service users, clinicians, the public and key partner organisations to develop a medium term strategy for the NHS. The strategy will align with the five domains of the NHS Outcomes Framework, identifying evidence-based, optimum, clinical pathways and changing services where necessary. This work will be underpinned by economic modelling to ensure we develop and deliver financially sustainable services for the future. Greater Manchester's work as part of Healthier Together will support and inform this work.

- *Service change* - Over time, the way services are delivered will evolve in line with new technology and clinical practice. NHS England will develop and oversee a framework for major service reconfiguration that will set out the roles, responsibilities and interfaces between the different organisations across the health and care system that will operate from April 2013. The Area Team will support the application of this framework to Greater Manchester's work in the Healthier Together programme.

- *Allocations* - During 2013/14 NHS England will carry out a review of the approach to resource allocation, which will inform future allocations. In particular this will be an opportunity to consider the full breath of NHS England funding to make sure it is allocated in the best way to address inequalities and improve outcomes.

- *Pricing* - In 2013/14, the production and dissemination of the tariff will remain a DH responsibility, with NHS England and Monitor taking joint responsibility thereafter. National work in 2013/14 is primarily focused on working with Monitor to design and set the 2014/15 tariff and formal engagement is expected to begin from June onwards. NHS England will also agree priorities for the medium-term, and as part of NHS England's longer term strategy work, to develop a long-term approach to the development of the tariff.

**Greater Manchester Area Team Key Priority 11**

*Innovation, creation, diffusion and spread*

- *Innovation* – NHS England will deliver programmes for rapid diffusion and adoption of innovative ideas, products and services so that everyone can benefit from proven best practice, including disadvantaged groups. In 2013/14, the primary focus will be to embed *Innovation, Health and Wealth* across the new commissioning system, deliver NHS England’s contribution to the UK Genomics Strategy and lead the NHS’s contribution to the UK Plan for Growth.

- *Research and Development* - NHS England has a mandate commitment to “ensure that the new commissioning system promotes and supports participation by NHS organisations and NHS patients in research funded by both commercial and non-commercial organisations, to improve patient outcomes and contribute to economic growth”. To carry forward this commitment NHS England is developing a research and development strategy early in 2013/14.

- *Academic Health and Science Networks (AHSNs)* – The Greater Manchester AHSN will develop as the local centre for innovation within the NHS. The network brings together expertise in education, research, informatics and innovation to translate research into practice in mental and physical health.

- *Academic Health Science Centre* – The Greater Manchester Area Team will support the Manchester Academic Health Science Centre in its re-bidding for national accreditation as an Academic Health Science Centre

| Key deliverables : Strategy, Research and Innovation | Timelines |
|---|---|
| NHS Publication of a long term strategy for the NHS, including a comprehensive primary care strategy | Products throughout 2013/14 |
| Oversee the priority service reconfigurations to ensure outcomes for people are improved | Throughout 2013/14 |
| NHS England flexible procurement programme for genomics strategy in place to sequence 100,000 genomes in UK in the next three years. | Quarter 4 2013/14 |
| Review of NHS allocations | Interim outputs July 2013<br>Final outputs July 2014 |

## 2.8 Clinical and professional leadership

2.8.1 Strong and diverse clinical and professional leadership is essential for high quality commissioning. CCGs have been established to ensure that clinical leadership is at the heart of local commissioning. NHS England will work to ensure that there is the right level of clinical and professional leadership in everything we do.

2.8.2 The Medical and Nursing Director in the Area Team, working alongside clinical networks and senates, will provide clinical leadership to NHS England activities locally and regionally and to the wider commissioning system.

*The NHS Nursing Strategy: Compassion in practice*

2.8.3 *Compassion in Practice* sets NHS England’s shared purpose for nurses, midwives and care staff to deliver high quality, compassionate care, and to achieve excellent mental and physical health and wellbeing outcomes. It builds on the enduring values of the NHS, and the rights and pledges of the NHS Constitution.

2.8.4 The strategy sets out six areas for action to be implemented over the next three years:

- *Staying independent, maximising wellbeing & improving outcomes*
- *Improving patient experience*
- *Delivering high quality care & measuring impact*
- *Building & strengthening leadership*
- *Right staff, right skills, right place*
- *Supporting positive staff experience*

**Greater Manchester Area Team Key Priority 12**

*Compassion in Practice*

Compassion in Practice will be embedded as part of the Greater Manchester clinical collaborative networks for safeguarding adults and children involving nursing leaders in primary, secondary and mental health care .

*The 7 day services review*

2.8.5 Our aim is to promote a comprehensive health service, increasing access to the right treatment and coordinating care around the needs, convenience and choices of patients, their carers and families – rather than the interests of organisations that provide care.

2.8.6 *Everyone Counts* set out plans to move towards routine services being available seven days a week. The first stage objective is to establish a forum and publish a report, in the autumn of 2013, identifying how there might be better access to routine services seven days a week. In this first phase, the review will focus on improving diagnostics and urgent and emergency care. It will include the consequences of the non-availability of clinical services across the seven day week and provide proposals for improvements.

*Urgent and Emergency Care Review*

2.8.7 The Urgent and Emergency Care Review aims to develop a national framework to enable clinical commissioning groups (CCGs) to commission high quality urgent and emergency care services across NHS England for April 2015. The first stage of the Review is to publish high level principles in 2013. The most serious emergencies require rapid access to highly specialised skills and equipment; however, many less serious cases can be safely treated in community settings.

*Clinical senates and networks*

2.8.8 Clinical senates will bring together a range of professionals to take an overview of health and healthcare for local populations and provide CCGs, health and wellbeing boards and NHS England with strategic, independent advice and leadership on how services should be designed. They will draw on a variety of health and wider care perspectives to provide the best overall care and outcomes for people, including those of professionals who sometimes go unheard.

2.8.9 NHS England will also host four Strategic Clinical Networks, these are as follows:

- Cancer
- Cardiovascular
- Maternity and children
- Mental health, dementia and neurological conditions

*Leadership on health inequalities, equality and diversity*

2.8.10 There are still too many longstanding and unjustifiable inequalities in access to services, quality of care, health outcomes and patient experience. It is our ambition that everyone receives excellent care, which takes account of their background, who they are and where they live.

2.8.11 During 2013/14, NHS England will re-launch the Equality Diversity Council (EDC) with a structured work programme, embedded within each of the NHS England directorates, which will support the promotion of equality and the reduction of health inequalities across society. Within this period, the Equality Diversity System (EDS) will also be refreshed to embody the values of the NHS Constitution and help NHS organisations to reduce inequalities in health. The EDS will be rolled out to the NHS to help promote equality and reduce health inequalities. It will form the basis of NHS England's equality objectives for the forthcoming business planning period, in collaboration with the NHS EDC. We have also established an Equality and Diversity Group to improve the diversity of NHS England itself.

*The NHS Leadership Academy*

2.8.12 The NHS Leadership Academy is a system wide body, whose vision is to be recognised as a national centre of excellence for leadership development and talent management in the NHS. Its mission is to develop outstanding leadership in health to improve the quality of services and outcomes for everyone.

*NHS Improving Quality*

2.8.13 NHS Improving Quality (NHS IQ) has two overarching priorities; to drive the implementation of the NHS Outcomes Framework through effective improvement programmes, and to build improvement capacity and capability across the whole of NHS England.

| Key deliverables: Clinical and professional leadership | Timelines |
|---|---|
| 7 day service review report published | Autumn 2013 |
| Urgent and Emergency Care Review: high level principles published | Spring 2013 |
| Commencement of 70% of the actions set out in 'Compassion in Practice' (our three year nursing strategy) | By April 14 |
| Delivery of Leadership Academy core programmes to 2,000 clinical and non-clinical staff | March 2014 |

## 2.9 World class customer service: information, transparency and participation

2.9.1 NHS England is committed to transforming the way information is made available to the public and wider healthcare system. We will improve data and information availability to better support public and patient participation.

*Intelligence: supporting decision making and choice throughout the service*

2.9.2 Health and care data represents one of our greatest public assets and putting it to work is key to improving outcomes for all people. We will build a modern data service, through the *care.data* programme, which will provide timely, accurate data linked across the different components of the patient journey and the outcomes resulting from treatment.

*Patient and public voice: putting the citizen at the heart of the NHS*

2.9.3 NHS England aims to create the conditions for an equal, balanced and reciprocal relationship between citizens and the NHS. A national Civil Society Assembly will be established to encourage collective participation. NHS England will develop a coherent, linked package of shared-decision making aids so that people can actively participate with their clinicians in making choices about their care and treatment. We will make available personal health budgets for people who could benefit from them, subject to evaluation of the national pilot programme.

*Patient insight, including roll out of the friends and family test*

2.9.4 A deeper understanding of how users of NHS services view aspects of the care they receive is essential to make services better. National staff and patient surveys facilitate the benchmarking of services, and are particularly valuable in helping improve the experience of groups who may be socially disadvantaged.

2.9.5 As set out in the government's NHS Mandate, one specific aspect of this will be the roll out of the Friends and Family Test. This will enable staff and patient feedback to be gathered in a more responsive and granular way. The Friends and Family test information will be shared routinely through the Quality Surveillance Group.

*Customer relations: Giving people control and choice when they want it*

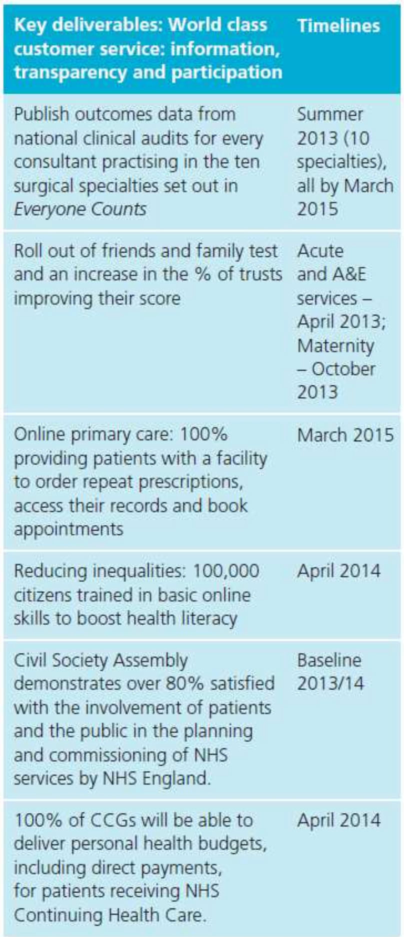
2.9.7 To be a truly patient centred service, the choice and control that the NHS offers to people in the services they receive must be maximised. We will work to make the NHS Constitution a reality, including the right for people to make fully informed decisions about how, when and where they access healthcare. This includes choice both at the point of GP referral and along the care pathway.

*Strategic systems and technology: digital first*

2.9.8 The Health Online Programme makes use of modern technology to transform the service offer of the NHS, empowering patients and citizens to take control and make informed choices. As part of this, people will have online access to their health records if they want it, by 2015. The ‘Paperless NHS’ programme includes the re-launch of Choose and Book which aims to make electronic referrals universally and easily available to patients and their health professionals for all secondary care services by 2015.

**Communicating patient and public values**

2.9.9 NHS England will put in place the essential communications infrastructure to support its national, regional and area teams. Commissioning Support Units will provide a joined-up communications service on behalf of NHS England’s regional and area teams, so that we engage effectively with local stakeholders, public and media. We will deliver a programme of stakeholder and learning development events to share key information, motivate and engage with key audiences. As part of this, NHS England will build a website that is robust and engaging for both the public and our staff.



| Key deliverables: World class customer service: information, transparency and participation | Timelines |
|---|---|
| Publish outcomes data from national clinical audits for every consultant practising in the ten surgical specialties set out in *Everyone Counts* | Summer 2013 (10 specialties), all by March 2015 |
| Roll out of friends and family test and an increase in the % of trusts improving their score | Acute and A&E services – April 2013; Maternity – October 2013 |
| Online primary care: 100% providing patients with a facility to order repeat prescriptions, access their records and book appointments | March 2015 |
| Reducing inequalities: 100,000 citizens trained in basic online skills to boost health literacy | April 2014 |
| Civil Society Assembly demonstrates over 80% satisfied with the involvement of patients and the public in the planning and commissioning of NHS services by NHS England. | Baseline 2013/14 |
| 100% of CCGs will be able to deliver personal health budgets, including direct payments, for patients receiving NHS Continuing Health Care. | April 2014 |

## 2.10 Developing commissioning support

2.10.1 Locally designed, clinically-led commissioning will be at the core of the healthcare system. Success will depend on clinicians focusing on the differing needs across their local population and able to devote time and clinical leadership to addressing those needs. This will require access to excellent and affordable commissioning support services.

2.10.2 Developing a robust market for the provision of commissioning support services should widen the skills and resources available to commissioners and create efficiency in the marketplace. NHS England will design and publish in June 2013 a strategy to develop affordable and sustainable commissioning support services, setting the standard for excellence. This strategy will also include a quality regulation framework to ensure sustainability of the market.

2.10.3 The current NHS England-hosted CSUs are likely to form a key part of this market and will be supported and developed to become commercially viable by March 2016.

2.10.4 Over the past 18 months, CCGs have been working with CSUs to define and specify their requirements. NHS England's role in hosting these organisations includes assuring they are viable, supporting their development as well as developing a future market for commissioning support services.

2.10.5 NHS England must provide assurance that CSUs are commercially robust, and that potential commissioning and financial risks are well-managed. At the same time we need to maximise their ability to become freestanding, responsive commercial enterprises. We are developing fair, balanced frameworks for monitoring and assuring that CSUs are as effective as possible.

2.10.6 NHS England is launching a development programme to support CSUs to become effective and efficient organisations. This programme will focus on leadership development, data and information management and the procurement of potential delivery partnerships.

| **Key deliverables: Developing commissioning support** | **Timelines** |
|---|---|
| Robust processes are in place to assure the performance of all CSUs (service quality and financial) | From April 2013 |
| Final strategy for the development of commissioning support services published | November 2013 |
| CSUs commercially viable and externalised | March 2016 |
| Creation of a diverse and responsive commissioning support market | March 2016 |
| Positive feedback from customers on services provided by CSUs | Twice a year |

## 3.0 Developing NHS England

3.1 NHS England takes on its full responsibilities from April 2013, however 2013-14 will be a year of transition in a number of areas. As a new organisation there is a considerable focus for the first year on establishing and investing in its most vital resource – its people. This section sets out how we aim to achieve this.

### *Staffing*

3.2 NHS England has eight directorates from which to draw resources to help deliver improved outcomes for people. The majority of our functions will be carried out at a local level through four regional teams and twenty seven area teams, supported by the operations directorate.

### *Organisational development*

3.3 Our approach to organisational development will be central to our success. It is important that we reinforce and develop a single organisational culture and build a shared vision of improving outcomes for people.

### *NHS England Governance*

3.4 Delivering NHS England business is a large-scale complex task. A corporate programme office has been established to provide a resource to the organisation in terms of project support, as well as providing assurance to the Board regarding corporate performance and business plan delivery. Risk identification and mitigation is an important element of this and will be managed and reported on using the Board Assurance Framework.

*Public and Parliamentary accountability*

3.5 NHS England is accountable for delivering the mandate set for us by the government to respond to correspondence, Parliamentary questions and complaints, and as a statutory body we have formal duties to respond to Freedom of Information and Data Protection Act requests. Teams have been established to respond to briefing requests from various stakeholders, and FOI requests and calls from the public. A formal protocol has been agreed with the Department of Health setting standards for timeliness and quality that we will meet.

*Equality and Health Inequalities Strategy – including the Equality Diversity Council and the Equality Diversity System*

3.6 One of NHS England's central commitments is to promote equality across the NHS and reduce health inequalities in access to, and outcomes from, healthcare services. It is our ambition that everyone receives care that takes account of their background, who they are and where they live. NHS England will publish equality data and information using EDS, that demonstrates how NHS England is meeting the Public Sector Equality Duty (PSED) and performance against its agreed equality objectives. We will also include an assessment in the NHS England annual report of how well NHS England and CCGs have met their legal duties regarding health inequalities.

*Assessing our success in building the new organisation*

3.7 It will be important to measure how successfully we have met the objectives outlined above. We will do this through a range of measures, including feedback from all our partners. We are already working with NHS clinical commissioners to co-produce an independent 360 degree survey to provide feedback to NHS England from every CCG in the country which will form part of these measures, along with a regular staff survey; and other indicators under development.

## 4.0 CONCLUSION & RECOMMENDATION

4.1 This paper summarises the business plan priorities of NHS England. It also seeks to clarify specific elements of responsibility which local partners might expect of the Area Team. A good deal of the content represents intentions and work which is already underway and will be familiar to local partners. Beyond that work described for which the Area Team will be the delivery partner, the opportunity remains for local partners to engage, inform and influence that work which is being progressed at the national level.

4.2 The Health & Wellbeing Board is invited to consider the priorities of NHS England (formally the National Commissioning Board) through the Local Area Team to understand how these priorities might best support the aims of the board and the Joint Health and Wellbeing Strategy.

stroke.org.uk

Stroke
association

# Feeling overwhelmed

## The emotional impact of stroke

LIFE AFTER STROKE **CAMPAIGN REPORT**
**Summer 2013**

# Contents

# Foreword

## Stroke is life-changing and the emotional impact can be far-reaching for both the stroke survivor and their carer. But it doesn't seem to be much talked about. We'd like to change that.

There are approximately 1.1 million stroke survivors living in the UK.[1] *Feeling overwhelmed*, the third report in our Life After Stroke campaign series, highlights the emotional impact of stroke on survivors, their carers and families. We call on those who plan and provide health and social care to work with us to address this serious and underappreciated problem.

Stroke is a sudden, life-changing event. Stroke survivors grieve for the life and identity they have lost so suddenly and unexpectedly. They often feel intensely frustrated and angry at being unable to carry out the simple, everyday tasks they used to take for granted. Anxiety and depression can also result from the damage caused by the stroke itself. Carers are suffering too and are often left to cope alone.

In this report you will hear how only two in ten stroke survivors and one in ten carers received the support they needed to cope with the emotional aspects of stroke. The Stroke Association's services offer emotional support but currently we are only commissioned to see around 40% of stroke survivors in the UK.[2] We support many more through our UK-wide helpline, information leaflets, stroke.org.uk and stroke clubs. But we want to reach everyone affected by stroke. To do this we need your help.

Our report shows that improving emotional support for people affected by stroke is not necessarily about spending more money. Signposting and referrals to existing services (including free sources of information), combined with duplicating best practice examples, can deliver support that puts the needs of stroke survivors and carers at the centre of stroke care. Underpinning this report you will see mention of the *Stroke Survivors' Declaration*, written by 120 stroke survivors across the UK it sets out the level of support people affected by stroke expect.[3]

If you are involved in planning or providing health and social care your role is crucial in helping stroke survivors and carers deal with the emotional impact of stroke. We can help you to signpost stroke survivors and carers to the information, practical advice and emotional support they need. We are building a community of people who care about stroke and want to see people make their best recoveries. Please see our calls to action on page seven and sign up online to show your support, hear about best practice and access free sources of information.

Show your support at **stroke.org.uk/campaigns/signup** or by scanning this code using a smart-phone.

**Jon Barrick**
Chief Executive
Stroke Association

# Key findings of this report

## The emotional impact of stroke can be just as devastating as the physical effects.

During the autumn of 2012 we surveyed people affected by stroke to find out about the emotional impact that stroke has had on their lives and whether they had received the support they needed to help them cope. We received over 2,700 responses and this report is based on what they told us.

Please note that all data presented is UK-wide, however breakdown by nations can be found online at **stroke.org.uk/campaigns/feeling-overwhelmed**

### What stroke survivors told us

- Only two in ten were given information, advice and support on coping with the emotional aspects of stroke.
- Almost two-thirds agreed or strongly agreed that their emotional needs were not looked after as well as their physical needs.
- Although 67% had experienced anxiety and 59% felt depressed, over half of those who responded to our survey did not receive any information, advice or support to help with anxiety or depression.
- Nearly half said their relationships or contact with friends and families had been put under strain.

### What carers told us

- Two-thirds had experienced difficulties in their personal relationships with a husband, wife or partner as a result of stroke. Of these, one in ten had broken up with their partner, or considered doing so.
- Caring gets harder as time goes by. For those who have been caring for up to three years 48% said they were stressed by caring, but when they had been caring for seven years or more 69% of carers said this was the case.
- Three-quarters agreed or strongly agreed that they put the needs of the stroke survivor above their own needs.
- Although 79% had experienced anxiety and 56% felt depressed, two-thirds did not receive any information, advice or support to help with anxiety or depression.

Everyone reading this report can improve the emotional wellbeing of stroke survivors and carers by recognising the serious emotional impact of stroke and by being confident in signposting people to further help.

# Why focus on the emotional impact of stroke?

Both stroke survivors and their carers can feel overwhelmed by worries, fears and emotions as they struggle to cope with the aftermath of a stroke. If these feelings are not recognised and addressed at an early stage they can lead to more complex and costly health and social care interventions.

**Previous research has shown that:**

- Healthcare costs for patients with long-term conditions who also have depression are typically 45% higher than for those without.[4]

- Depression also increases the risk of cardiovascular disease (including stroke) by one and a half times as compared with the general population, so stroke survivors presenting with depression are more likely to have another stroke.[5]

- Over half of carers for someone who has had a stroke have experienced mental health problems.[6]

- However, over half of stroke units in England, Wales and Northern Ireland still have no access to psychology services at all.[7] In Scotland only a third of stroke units have access to clinical psychology services.[8]

- Work by the Stroke Improvement Programme (in England) indicates that an investment of around £69,000 in psychological care through a clinical psychologist-led service, with clinical psychology assistant support and an appropriately trained multi-disciplinary team, may deliver a benefit of around £108,000 to the NHS and social care in around two years.[9]

Each of the four UK national governments has also put a strong focus on emotional wellbeing:

- In England, the Department of Health's new *Cardiovascular Disease Outcomes Strategy* (2013) calls on commissioners and providers to pay particular attention to the emotional and psychological support of stroke survivors and carers.[10]
- In Northern Ireland, *Transforming Your Care* (2011) includes recommendations around promoting mental health and wellbeing.[11]
- In Scotland, the *Better Heart Disease and Stroke Care Action Plan* (2009) recognises the emotional impact of stroke and the need for better access to psychological support in hospital and the community.[12]
- The Welsh Government's *Together for health – Stroke Delivery Plan* (2012) states that Local Health Boards should provide robust psychological support in hospital.[13]

# Our calls to action

All stroke survivors, their carers and families deserve the best possible support to help them cope with the emotional impact of stroke. Together with them, we call on those who plan and provide health and social care to:

1. Recognise that emotional support is just as crucial for recovery as physical rehabilitation after stroke, and make sure that services are in place to support this.

2. Ensure all stroke survivors, their carers and families are given accurate, timely, and accessible information at all stages of their stroke journey to help them adjust to the emotional impact of stroke.

3. Ensure that all stroke survivors receive a regular review of their health and social care needs that should include an assessment of their emotional and psychological wellbeing. Survivors' emotional wellbeing should also be a key part of their health and social care plans.

4. Recognise carers as "partners in care" and include them in the stroke survivor's ongoing stroke journey towards recovery, whatever their individual goals.

5. Ensure all carers are aware of, and receive, a carer's assessment. This assessment should include a review of their emotional wellbeing and result in them getting the help they need.

6. Ensure stroke survivors who are affected by aphasia can easily access support, from community based services, other people with aphasia, or from stroke clubs.

7. Increase investment in the provision of clinical psychologists, who should ideally be part of the multi-disciplinary stroke team, both in hospital and in the community.

8. Support children and younger stroke survivors from diagnosis, through sign-posting to peer support groups and ensuring a seamless transition to adult services. This must include more effective assessment and treatment of the emotional and psychological impact of stroke on children and younger stroke survivors and their families.

9. Ensure the monitoring and publishing of data on the long-term emotional experiences of survivors, carers and families to show if and how they are accessing emotional support, for how long, and whether their needs are met. This should look at people's experiences beyond the stroke pathway and focus on the stroke journey taken by survivors and carers.

10. Ensure that health and social care providers share best practice. If you're particularly proud of your service or the work that you're doing to help people affected by stroke please get in touch with us at **campaigns@stroke.org.uk** so we can share your best practice with others.

# Patricia's story

**Patricia worked in London in a high-powered job. Already signed off temporarily due to a lung condition and in hospital being treated for an aneurysm, it was a triple blow when she had a stroke. Patricia still can't quite believe it happened to her.**

She was rushed to a specialist stroke unit where she received life-saving, clot-busting drugs. She spent one month in hospital and her treatment was good. Despite this, she was left paralysed down one side, and the stroke also affected her speech.

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

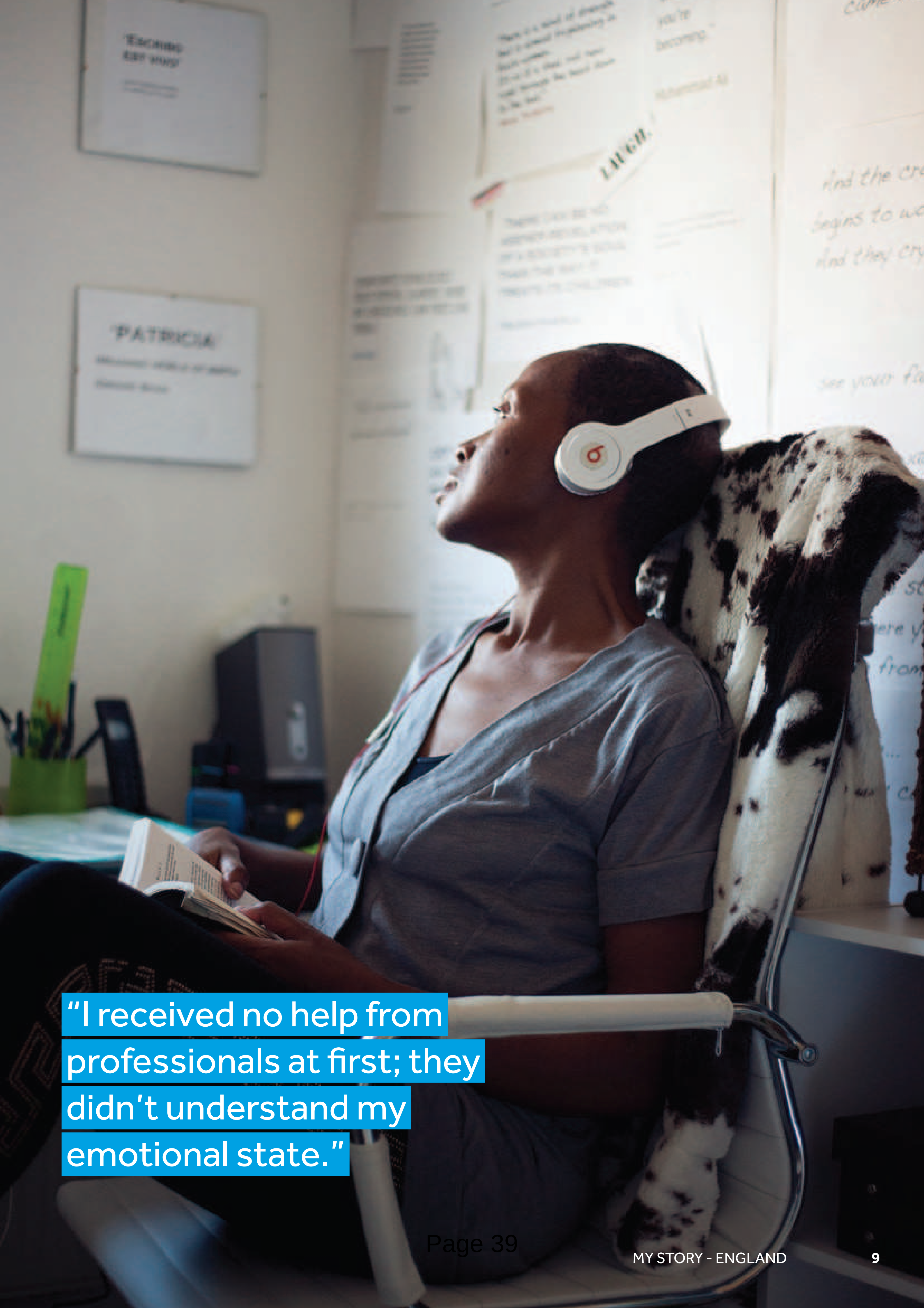
"I received no help from professionals at first; they didn't understand my emotional state. When I cried, they didn't know what to do; despite the fact that I had been told by them that a right-sided stroke would directly affect my emotions."

She also found it hard to talk about the stroke with friends and family. "I still don't like to burden them with it." She says she "wears a mask", even with her brother who lives close and comes round to help her when she can't cope. Instead, Patricia talks about her feelings through poetry. "This was how my family found out about how I really feel."

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

But her stroke journey isn't over yet. "People say things like 'oh, you're almost there, you're almost recovered', but they don't understand that the last 5% of recovery is the hardest. Each time I've taken a step forward, something has knocked me several steps back, and the last 5% of my recovery feels more like 50%."

"I don't like to burden my friends and family with my stroke. Around them I wear a mask."



> “I received no help from professionals at first; they didn’t understand my emotional state.”

# The emotional strain on stroke survivors

The emotional impact of stroke can be just as profound as the physical effects.

> "The emotional side of stroke is a wasteland. Many of the emotional issues arrive not at the time of the stroke, when all you are doing is trying to get well again physically, but it's months later when the reality hits that you will never be the person you once were."
>
> *A stroke survivor*

Throughout this report people recount the daily problems, worries and fears they have experienced, and how support and understanding is at best patchy and at the worst absent as they struggle to recover.

The full extent of the emotional impact is not always obvious until the stroke survivor returns home and the reality of the situation sinks in.

Stroke can leave a long-term emotional legacy, which survivors and carers are usually totally unprepared for. The journey to recovery taken by survivors and carers continues even when the formal help from health and social care tails off.

While seven in ten survivors agreed or strongly agreed that they felt well looked after and cared for when in hospital, more than four in ten felt abandoned after leaving.

## The day to day emotional effects of stroke

Almost three-quarters of stroke survivors said they felt less confident after their stroke. They grieve for the life they've lost and feel intense frustration at not being able to complete simple, everyday tasks that others take for granted. These hidden, but very real, worries can change relationships with partners and friends, leading to further social isolation.

To make matters worse, many stroke survivors in our survey (63%) said their greatest fear is having another stroke. They also have other concerns: for example, 48% of survivors reported a lack of motivation or feeling angry. Three-quarters of all strokes happen to people over the age of 65, who may also be suffering from a range of other health conditions which can also affect their emotional wellbeing.[14]

However, in our survey, the emotional impact of stroke was particularly evident for those aged 30-59 years who reported high levels of anxiety (76%), depression (69%) and fear (55%).

Many survivors are acutely aware of the impact of the stroke on their partner and family, and feel that they have become a burden. Yet, despite this, 69% said they still felt they "had to stay strong for their family". This report calls for searching discussions by all involved in stroke about the often harrowing emotional impacts of the condition, to help everyone touched by stroke adjust to their new reality.

## Stroke, anxiety and depression

"I would not wish what I've been through on my worst enemy. I've battled with depression and fatigue but I no longer consider suicide on a daily basis. I can talk and I make myself do things. Life is a constant daily struggle."

*A stroke survivor*

When the part of the brain that normally controls emotions becomes damaged by a stroke, the result can be a change in how people think, feel or behave.

Stroke survivors can experience a range of emotions following a stroke, such as anxiety, depression, anger and frustration. They may become more emotional than usual or have difficulty controlling emotions ("emotionalism"). Moreover, a stroke can cause changes to personality so that to others the survivor seems like a different person.

Given the scale of the problems reported by respondents to our survey, it is clear that a lot more needs to be done to support the emotional wellbeing of stroke survivors and their carers. If emotional problems are not identified and addressed early, they can lead to more serious psychological problems, such as anxiety, phobia and depression. At worst they can result in a suicide.[15]

The regular assessments that should form part of the stroke pathway can pick up emotional issues if the right questions are asked. It is then key to ensure that people get access to the appropriate level of emotional support, or more serious emotional problems can result.

In our survey 67% of stroke survivors reported suffering anxiety and 59% felt depressed. Our findings reinforce other studies which found high rates of depression in stroke survivors.[16]

Stroke can be a traumatic and frightening event and stroke survivors can experience Post-Traumatic Stress Disorder (PTSD). One study found that up to one-third of stroke survivors experience the symptoms of PTSD.[17] Again early identification is critical.

***Stroke Survivors' Declaration* point seven:**
My mental health and physical needs will be recognised and I will be able to access the relevant support. [18]

## The wider healthcare cost implications

Healthcare costs for patients with long-term conditions who also have depression are typically 45% higher than for those patients not presenting with depression.[19]

When a physical illness like stroke is accompanied by mental illness it worsens outcomes such as life expectancy.[20]

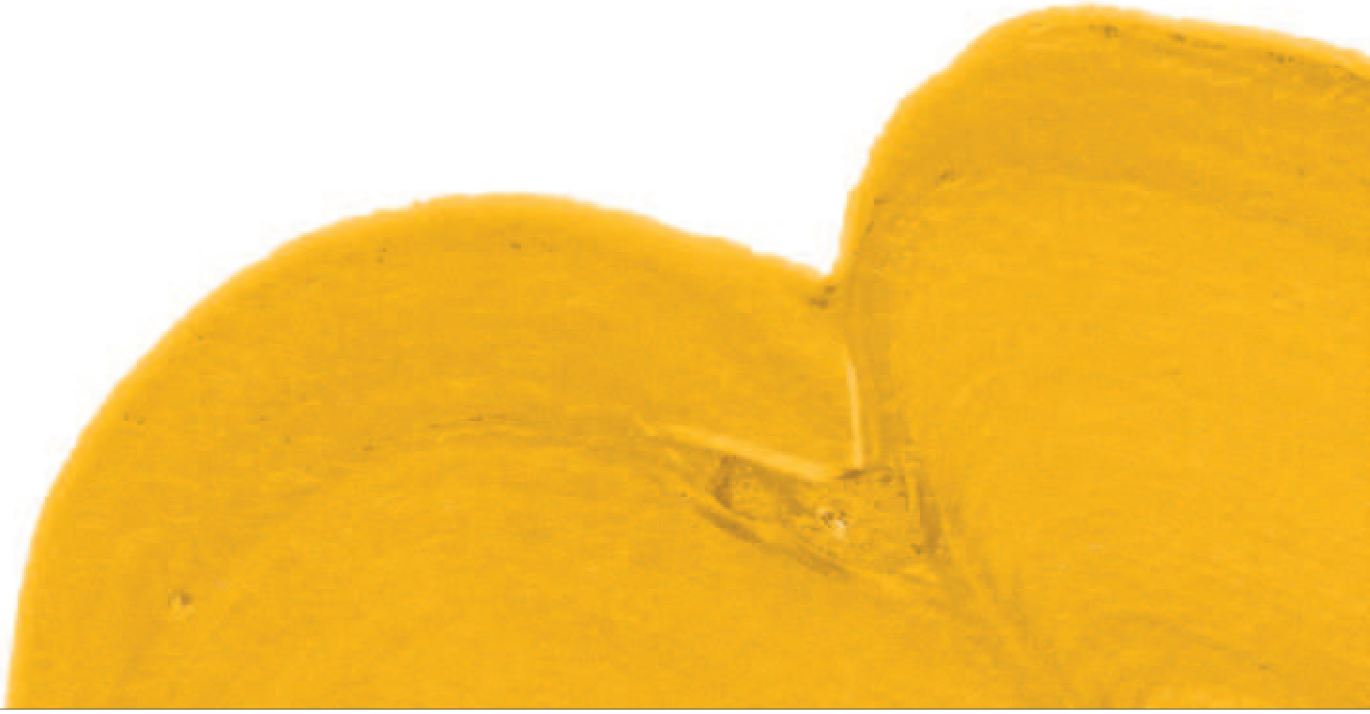
Stroke survivors who are depressed are four times more likely to die within six months as those who are not.[21]

Depression also increases the risk of stroke by one and a half times, so stroke survivors with depression are more likely to have another stroke.[22] But current provision to treat stroke survivors with depression can be inadequate.

There is also a strong economic case for investment in psychological support.

Work by the NHS Stroke Improvement Programme indicates that an investment of around £69,000 in psychological care through a clinical psychologist-led service, with clinical psychology assistant support and an appropriately trained multi-disciplinary team, may deliver a benefit of around £108,000 to the NHS and social care in around two years.[23]

Psychological support is lacking across the UK despite each of the four national governments putting a strong focus on emotional wellbeing. Over half of stroke units in England, Wales and Northern Ireland still have no access to psychology services at all.[24] In Scotland only a third of stroke units have access to clinical psychology services.[25]



## The importance of information

> “I was offered tablets for depression, when I wanted therapy and verbal support to deal with the changes in my role.”
>
> *A stroke survivor*

Information empowers people; it helps them to understand what has happened, plan for the future and better manage their situation. Despite this, half (52%) of stroke survivors participating in our survey did not receive any information, advice or support with anxiety and (56%) reported a similar lack of help with depression.

These findings chime with those of our 2010 research, where four in ten (39%) survivors reported their need for help with emotional problems was unmet.[26] (See pages 38-39 for further information).

**Call to action for those who plan and provide health and social care**

Ensure that all stroke survivors receive a regular review of their health and social care needs that should include an assessment of their emotional and psychological wellbeing. Survivors’ emotional wellbeing should also be a key part of their health and social care plans.

# Ann's story

**Neil was a fit, active man so it was a total shock when he had a stroke; and then another. His second stroke, the most severe, left him with slow and slurred speech, and he had to get around the house on his hands and knees.**

But this story isn't about Neil. It is about Ann, his wife.

Ann feels as if she has a different husband now. His personality has changed and, for a year, Ann grieved for the man she had lost, the man he used to be.

Finances became a worry. They had a mortgage to pay and Ann wasn't sure if Neil ever would be able to return to work. Neil went back to work six months after his stroke, part time. But their entire relationship had changed. They argued a lot and the worry and grief began to make Ann physically ill.

Neil didn't realise he'd changed at first, but once he did he told Ann he wouldn't blame her if she left him. She was just thankful that he was still alive and she slowly felt more able to accept the "new him".

Neil was beginning to sink into depression and Ann, realising, sought help from a local mental health team which helped get him back on track. But Ann, who herself felt incredibly isolated, worried and low, wasn't offered any support at all, other than from their family.

After reading an article in the local paper, Ann was put in touch with a local stroke club. It was through the club she realised they weren't alone, that other people were going through a similar experience and that personality change could accompany a stroke. The Stroke Association also put Ann on a course about how to cope after stroke, which helped her enormously.

Neil still struggles with the fatigue, and gets frustrated because he used to be so active. "Neil's still not the man I married but he's slowly coming back; he's becoming 'him' again.

"Things are beginning to get easier, but it's been a long, hard journey and it's not over yet."

Her husband's personality changed and, for a year, Ann grieved for the man she had lost, the man he used to be.

“Things are beginning to get easier, but it’s been a long, hard journey and it’s not over yet.”

# The emotional impact of stroke on carers

Carers play a vital and very demanding role. Without them many stroke survivors would be unable to live independently.

Currently less than a quarter of carers feel supported after the stroke survivor they care for leaves hospital. Recovering from stroke is not just about providing support along the stroke pathway – it is about supporting stroke survivors and their carers along their whole personal stroke journey, however long that takes.

Perhaps the worst news is that being a carer doesn't seem to get any easier. In our survey we asked people if they were stressed by caring. For those who had been a carer for up to three years 48% said they were stressed by caring, but when they had been caring for seven years or more 69% of carers said this was the case. Two-thirds of all carers who responded to our survey had experienced difficulties in their personal relationships with a husband, wife or partner as a result of stroke. Of these, one in ten had broken up with their partner, or considered doing so.

We also need to acknowledge that many stroke survivors and carers will have multiple health problems and these issues are likely to increase with an ageing population and the increase in diseases like diabetes, which is a known risk factor for stroke. The need to support carers properly will therefore become an even larger issue.

> "My husband's stroke has been the most devastating experience of my, and his, life. First you have to rebuild the survivor and their life. Then your joint lives together and, if you have any energy left, you can have a go at remembering who you are."
>
> *A carer*

## The challenges faced by carers

Carers of stroke survivors face many challenges. Many carers are not getting the support they need, and their own health is suffering. They care out of duty and love but usually without any training, information or support, and they learn their caring role as they go along. Carers have told us how they feel guilty or selfish for finding it hard to cope or wanting time for themselves.

Too many carers are not receiving the information or support they need to help them adjust to life after stroke. Carers are also exhausted – eight in ten tell us they don't have enough time to themselves and six in ten are not getting enough sleep.

Caring can be physically demanding as it involves helping stroke survivors with tasks like washing, dressing and lifting. As a result, carers can experience a range of physical problems, which may include tiredness, back strain from lifting and illness. Over half of the carers in our survey also told us they have difficulty communicating with their partner because they have cognitive and/or speech deficits following their stroke.[27]

> "No one really realises how I am suffering, my husband comes across to people that don't know him as fine and healthy, but they don't realise he looks like my husband but the stroke took his personality away. I am suffering as he now hates me and because of his cognitive problems he doesn't realise I am here to help him."
>
> *A carer*

But 64% of carers said that the emotional impact of stroke was by far the hardest thing to cope with. Our survey shows that levels of anxiety and depression are as high for carers as for stroke survivors. Over half of carers for someone who has had a stroke have experienced mental health problems.[28]

Carers are entitled to an assessment of their needs, but many don't know how to go about getting one. Only a quarter told us they would know where to get an assessment.[29] When they do find out how to, many are told that they are ineligible.

***Stroke Survivors' Declaration* point ten:**
The impact of my stroke on my carers will be recognised. They will have access to appropriate information and services to help them understand and make adjustments. [30]

## How stroke affects carers emotionally

> "He is like Jekyll and Hyde, going from a loving husband to someone constantly belittling and criticising, which is very difficult to deal with. I am now on anti-depressants and have been for the last year."

*A carer*

Caring for a stroke survivor can be emotionally demanding. Survivors can find it difficult to understand, or communicate what they would like or how they are feeling. They may also feel depressed, have mood swings and vent their anger on carers. Carers responding to our survey also had a range of emotions as a result of stroke occurring in their families, including frustration (84%) and anxiety (79%).

They were also more likely than stroke survivors to feel angry, with over six in ten carers reporting this compared to half of stroke survivors. A number of respondents told us that they needed time to grieve for the person they had lost and the plans they had for the future, but there is often no recognition of this.

> "After 18 years of looking after my husband I seem to be going through another stage of depression and frustration having to still ask for financial assistance for respite. I feel it is an uphill struggle even now."

*A carer*

Six in ten carers did not receive any information, advice or support to help with anxiety and seven in ten said the same for help around depression.

Fewer than two in ten carers were given information on coping with the emotional aspects of stroke. By delaying asking carers about these issues and how they are coping we are storing up future problems that will affect both the carer and the stroke survivor.

Enquiring after the emotional wellbeing of carers makes good sense and should be a priority, particularly as so much of what can be provided, in terms of support, costs very little.

## What happens after discharge from hospital?

> "We were initially strongly supported by the Early Discharge Team. A little way down the line the support is tailing off and I have to go and look for it myself as my husband has become severely depressed and attempted suicide. "
>
> *A carer*

Only one in five carers was asked if they would take on caring responsibilities. Many carers told us that there was an expectation from health and social care professionals that they would be the carer, and they felt ill-prepared to take on the role.

According to one study, one month after the stroke survivor was discharged from hospital 33% of carers reported feeling ill-prepared to take on their caring role. After nine months this had risen to 72%.[31]

We believe that there is an important role for training here. Providing carers with training has been shown to improve their psychological outcomes and reduces the total health and social care costs.[32] The Stroke Association can provide this kind of training.

Not only do carers feel unsupported and stressed, but fewer than four in ten felt their knowledge of the stroke survivor was respected or valued. This is despite guidelines stating that carers should be viewed as an additional source of important information about the patient, both clinically and socially.[33]

Many carers told us that they feel they have to fight tooth and nail to get services they or their loved one needs.

> "I wish hospital and healthcare staff would listen to information about the patient and where possible and practical act upon it, instead of ignoring it. Most carers know more about the stroke survivor's physical and emotional problems than someone who has only just met them."

**Call to action for those who plan and provide health and social care**

Ensure all carers are aware of, and receive, a carer's assessment. This assessment should include a review of their emotional wellbeing and result in them getting the help they need.

# Inger's story

**Holding down a high-powered job at London's Royal Academy, responsible for a budget of millions, Inger was in the prime of her working life and watching her two children blossom into young women. But one day, home alone, she had a stroke.**

"I felt a rushing in my ears. At first I thought it was food poisoning, but I was so violently ill that I knew something was terribly wrong." Inger called an ambulance, begging them to stay on the line, fearing she would die.

She was taken to hospital, scanned quickly and a stroke was diagnosed – a bleed in the brain. But Inger had to leave hospital earlier than planned due to MRSA on the ward. Then it was down to her husband.

For six months Inger felt drained, slow and detached. "It was almost like being drunk, not having full control. The ramifications are horrendous. I still can't even relax with a book; reading is challenging. I wish people would realise that stroke is not an illness that can be treated and then you are well again, but a major life event that usually has lifelong effects."

Inger's now back at the Academy, but in a different role and only part time. "My job used to be part of my identity. I used to be a gold-standard multi-tasker, but the part of my brain that made me so good is damaged."

Since then, Inger's been diagnosed with Post-Traumatic Stress Disorder. Her partner became depressed. Intimacy became a big issue, both fearing a stroke could happen again. Inger worried he viewed her "as an invalid rather than a partner" but there wasn't any specialist counselling available.

Inger became involved in campaigning on stroke issues, and this has brought new and valuable friendships. But has she recovered? "My family sometimes talk about the road to recovery, but it's not a choice, or a lack of effort. It's a road to adjustment. Adjustment is the best hope for me."

"I used to be a gold-standard multi-tasker, but the part of my brain that made me so good is damaged."

“I wish people would realise that stroke is not an illness that can be treated and then you are well again, but a major life event that usually has lifelong effects.”

# How relationships, families and friendships feel the pressure

The impact of stroke is not restricted to individuals; it also throws families into crisis. The majority of stroke survivors and carers are emotionally affected by stroke but too many feel that they are facing its consequences on their own.

> "I never ever realised how difficult it would be looking after someone who has had a stroke, it has nearly destroyed our relationship, and has left me feeling angry, bitter and resentful."
>
> *A carer*

The emotional impact ripples through families. Nearly seven in ten stroke survivors told us they "try to stay strong for the family" while at the same time three-quarters of carers said they "put the needs of the stroke survivor above their own". With both parties not feeling comfortable or able to express how they really feel following a stroke, there can be a negative impact on partnerships and the entire family.

How the whole family cope following a loved one having a stroke is a largely unexplored area in research terms. Dr Caroline Kinney an NHS Stroke Clinical Psychologist says: "the impact on family systems is complex and therefore all members of the family need support in understanding what has happened."

## The importance of maintaining friendships after stroke

Friendship is not the same as family support or social support, but both can be invaluable to the stroke survivor and carer in that they represent the "real" world. However, in our survey over half of the stroke survivors who responded told us they were being treated differently by friends after their stroke.

> "I lost a lot of so-called friends who promised to come and see me but never did."
>
> *A stroke survivor*

> "I feel judged by friends and colleagues because although I appear fairly normal I still don't drive and find a lot of things exhausting. My husband is immensely supportive but I think friends think I am a pain."
>
> *A stroke survivor*

Some stroke survivors in our survey told us that friends seem uncomfortable or awkward around them and are unsure how to act. Keeping friendships was also mentioned as an issue by a number of stroke survivors, as some friends stop seeing them altogether, leaving them further socially isolated.

Research has highlighted that friendships are an untapped resource in supporting rehabilitation, self-management, participation and wellbeing following stroke.[34] Different friends can play different roles in helping to support stroke survivors in re-establishing their identity.

## How couples are affected

> "After my stroke, during recovery, my wife left me, and I now feel my world is falling apart around me. I feel totally depressed and unable to move on."
>
> *A stroke survivor*

Partners, friends and families are under strain and the build-up of frustration, anger, anxiety and exhaustion exact a particular toll on relationships. The emotional impact of stroke can lead to family breakdown.

In our survey, about a third have broken up with their partner or have considered doing so. 56% say their intimate relationship with their partner has suffered, and 34% feel they have no one to talk to. That's why well-coordinated support in the community is so important. Relationship difficulties were especially high for the 30-59 age group (61%), of whom 44% had broken up or considered doing so.

Couples can have different reactions to stroke depending on how the relationship was formed, what each person's expectations are, what their roles were, and what each partner feels they contribute towards their relationship. Some people feel rejected by their partner even though they have not been. Others feel that their partner should reject them. Conflict can also occur where a partner is trying to support a stroke survivor but is inadvertently causing them stress.

Clinical psychologists or stroke staff who have received psychological training, can provide counselling to couples to help them understand what is happening and support them to adjust to changes in their relationship. Other organisations, such as the Stroke Association and RELATE can also offer support to families.

> "Straight after my stroke I actually wanted to divorce my wife in order to leave her in a good financial position and without me as a burden."
>
> *A stroke survivor*

***Stroke Survivors' Declaration* point ten:**
The impact of my stroke on my family will be recognised. They will have access to appropriate information and services to help them understand and make adjustments.[35]

**Call to action for those who plan and provide health and social care**

Recognise carers as "partners in care" and include them in the stroke survivor's ongoing stroke journey towards recovery, whatever their individual goals.

# Marie and Paul's story

**Paul was in his fifties, the finance director of a large company and into sport. Then like "a thunderbolt from the blue" Paul had a stroke.**

In hospital Paul had problems communicating his needs. His wife Marie takes up the story. "He would say 'yes' to a cup of tea, but couldn't say what he'd normally say after that, such as 'are there any biscuits?' We had months of speech therapy."

It wasn't until they started speech therapy that aphasia was mentioned. "I'd never heard of the word; neither had some of the nurses; but we learnt what it meant very quickly." [36]

Back home, Paul didn't seem particularly distressed, but Marie was "terrified". Paul was on an emotional high. He started doing strange things such as eating soup with a fork and laughing at inappropriate times. "I don't think he understood what had happened. It was like being with a silly child."

Six months after his stroke, Paul went back to work, but lasted only three months because he couldn't concentrate and process information quickly enough. And the fatigue was "phenomenal".

There were days when Marie didn't feel she was in a relationship. "He's not the man I married. I would never have chosen to marry someone like this. People say I came off the rails and my anger was enormous." But the speech therapist was wonderful. "I could lean on her and cry and she understood."

"Paul's biggest problem after the stroke was lack of confidence and he still prefers me to answer the phone. But if I take the calls I'm doing him no favours."

Five years on, Marie and Paul are closer than ever, Marie is back at work and Paul's rehearsing speeches for two of his daughters' weddings!

"I cannot believe how lucky we've been, and that Paul is still improving. It's quite amazing. I'm so proud of him, and I wish I could help more people with aphasia because I've learned so much from this experience."

Paul went back to work, but lasted only three months because he couldn't concentrate and process information quickly enough.

“I cannot believe how lucky we’ve been, and that Paul is still improving. It’s quite amazing.”

# The devastating impact of aphasia

Aphasia is a common side effect of stroke. As many as one in three survivors will experience it.[37] Aphasia (also known as dysphasia) does not damage intelligence but does affect how someone speaks, understands, reads or writes.

> "I get frustrated when people can't understand me."
>
> *A stroke survivor*

Aphasia can be mild, and sometimes only affects one form of communication, such as reading. However, it is more common for several aspects of communication to be affected at the same time.

Aphasia can also sometimes cause subtle changes to emotional aspects of speech. For example, the stroke survivor's tone of voice may sound "flat" or their facial expressions may not vary. Stroke survivors with aphasia may also have difficulty in understanding humour or when to take turns in conversation. They may, or may not, be aware of these effects.

## What support do people with aphasia need?

> "I was discharged from hospital after 7 days of having my stroke, unable to speak, write, no letter recognition, barely able to walk. My children were 16 and 14 and they provided all of my care."
>
> *A stroke survivor*

Survivors with aphasia need specialist support from professionals who understand the challenges and emotional impact stroke and aphasia bring, as too often health and social care professionals haven't even heard of it. The Stroke Association has developed skills and experience to help people with aphasia.

> "Because I looked and still look physically well, I had hardly any help in dealing with inability to read, write, and understand speech, lack of confidence or emotional problems. My GP supplied medication and I had 3 sessions with a speech therapist and that is all."
>
> *A stroke survivor*

## Frustration and stress in people with aphasia

Many stroke survivors with aphasia reported the frustration they felt at trying and failing to communicate. They faced the same difficulties as other survivors in finding the right information at the right time but with the added difficulties caused by aphasia.

> “The treatment I received in hospital was awful. The small advice I received after leaving hospital was too soon and too in-depth as I suffered from aphasia.”
>
> *A stroke survivor*

Survivors with aphasia suffer higher levels of stress than other stroke survivors.[38] Aphasia is an important cause of low mood among stroke survivors but depression among people with aphasia is often under-diagnosed and untreated.[39]

Trying to communicate when important parts of your brain have been damaged needs a lot of effort. Not being able to express yourself clearly is very isolating.

> “It’s a journey that feels like it will never end, still to this day 2.5 years after, I suffer from cognitive and emotional issues. I feel I’m not there for my family anymore, it’s just so difficult. It’s a rollercoaster I can’t get off.”
>
> *A stroke survivor*

***Stroke Survivors’ Declaration* point two:**
I will be involved in decisions about my own care and have personal choices about, and control over, the support I receive. Services will be designed around my need to live as well as possible for as long as possible. If I have difficulties with speaking, writing or thinking, I will be able to appoint someone to advocate on my behalf.[40]

## Communication, carers and frustration

In our survey, many carers told us they know that the stroke survivor wants to express their feelings about changes following a stroke, but simply can't. Carers and partners also experience feelings of isolation and frustration and relationships can come under stress.

Carers are key. We know that carers need information and practical advice to better understand aphasia. They act as supporter and interpreter and may have to explain to professionals what the survivor needs.

Each survivor and carer needs tailored support depending on the extent of the disability the aphasia causes.

> "While his speech is now reasonable he can't take things in quickly. We find NHS staff ignore me as a carer and speak to my husband as though he can understand and make decisions immediately. Consequently we don't get the correct information after hospital appointments."
>
> *A carer*

> "We continually struggle to get medical professionals to recognise that he is not stupid when he gets treatment. He is ignored when he tries to communicate."
>
> *A carer*

Survivors reported that aphasia leaves them feeling isolated and alone. In turn, feelings of loneliness and low self-esteem can lead to long-term psychological distress.

Keeping in touch with friends and peers, feeling part of society and feeling "useful", are all important in helping stroke survivors make the best recovery they can.[41]

> "One of the worst effects on my son is loss of friends and workmates and his freedom. He cannot converse with his friends now. He cannot do things when he wants to, it always has to be when we, his parents, can do things with him; except for a few hours a week at a class which he pays for it is just home."
>
> *A parent of a stroke survivor with aphasia*

## Supporting people with aphasia

> "On discharge from hospital, I was left with a very confused and angry individual who did not really understand what had happened to him or the consequences. Help was very slow coming for his aphasia and there was absolutely no support for me."
>
> *A carer*

There is professional help available with some exceptional work going on. Specialist speech and language therapists (SLTs) assess communication difficulties and occupational therapists (OTs) can give practical help and advice on returning to work or participating in leisure activities. We are also aware of a pilot involving an individual SLT trained as a counsellor.[42] However, these are not available to all who might benefit.

Practising communication skills can also help. We heard from survivors who practise with friends or family, face to face or over the phone. In some areas communication groups and stroke clubs offer help to relearn communication skills, or simply offer conversation.

Some people with aphasia find singing can be a good form of expression, though this doesn't work for everyone. The part of the brain that we use for lyrics and music is different to the part we use for spoken language.

> "The public should be made aware of aphasia and the hidden problems of being unable to read and write. We were not told about this for about six weeks by any medical staff - we thought he understood but could not speak."
>
> *A carer*

However, relearning to communicate is only one of the issues faced by stroke survivors with aphasia. While the best already do this, we need to get to a situation where all professionals recognise that the serious emotional strain of stroke can be exacerbated by aphasia, and services need to be in place to support those affected.

**Call to action for those who plan and provide health and social care**

Ensure stroke survivors who are affected by aphasia can easily access support, from community based services, other people with aphasia, or from stroke clubs.

# Eoin's story

**Eoin was an independent 19 year old, a year through a business degree, when his world was turned upside down by a stroke.**

His dad took him to a hospital. Eoin can't fault the hospital care but outpatient care was a different story. Arriving at the Occupational Therapist's office, Eoin could see chairs and a desk, and a children's book. "I remember thinking, please don't let that be for me, but it was. It was humiliating. I tried to complete an exercise but couldn't. That destroyed me and I didn't want to know after that."

"I was still in contact with my friends; they listened, they were there. But I was so aware of the gap from the life that I knew and the one that my friends were still in."

Eoin tried to go back to his degree – "in an attempt to get back to my old way of life" – and then worked with his dad. This was probably when the depression started. "When you're in employment and find you're not able to meet expectations purely because of your stroke, it's difficult to keep a positive attitude."

His family were very supportive, but Eoin experienced feelings of guilt for being the person who "brought issues into the family".

Eoin went into denial. "I needed someone to make a connection, to break through the shield I'd put up, but no one ever did." He was given an assessment for depression at his GPs. "But I didn't answer truthfully because I knew intervention might come and I didn't want any."

Eoin's now in the third year of an Occupational Therapy degree, something he feels passionately about.

Finally, he feels comfortable starting a relationship, self-esteem used to be a problem before. But his journey could've been easier. "I needed someone, not necessarily a health professional, just someone, to knock down the wall I'd put up to protect myself. The wall did protect me; but it also stopped me dealing with things.

"But there comes a point when you've just got to stop looking back. If you want to move on with your life, you've just got to let it go."

His family were very supportive, but Eoin experienced feelings of guilt for being the person who "brought issues into the family".

“When you’re in employment and find you’re not able to meet expectations purely because of your stroke, it’s difficult to keep positive.”

# The impact of stroke on children and younger people

Stroke is an even more unexpected illness when it happens to children or younger people and everyone affected can feel emotionally devastated by the diagnosis.

> "Stroke services and support need to be improved for younger survivors. The whole NHS infrastructure and community care is only equipped to look after the older survivor."
>
> *A young stroke survivor*

Around 400 children a year have a stroke in the UK.[43] The lack of awareness among many professionals of stroke in younger people, means that it is often left to the family to pursue treatment, rehabilitation and appropriate support.[44]

## The emotional impact on younger stroke survivors

Dr Vijeya Ganesan, a paediatric neurologist who specialises in childhood stroke at Great Ormond Street Hospital, explains: "When a stroke first happens it can be very frightening to a child and hard for parents to explain what has happened to them. The effects of stroke on children are often long-term, invisible impacts."

Lots of people say that children recover better than older people but there is very little attention given to the "hidden" emotional or psychological impacts. As with adults mood disturbances are common but children are often not assessed for depression or anxiety, although many display symptoms. Behavioural issues are also common as, for example, a child might find it hard to readjust to school and so their behaviour will deteriorate.

Stroke in people of a younger age can also result in ongoing emotional issues which surface over time. New situations demand new expectations of younger people. For example, starting a new school, socialising, dating and work can all be triggers for emotional anxiety or even depression. Yet there has been little long-term research into the emotional impact on young stroke survivors.

We believe there needs to be greater recognition of the short and long-term emotional impacts on both the young person and family, both of whom should supported by professionals who understand the range of difficulties stroke can cause.[45]

> "Because I had my stroke when I was a young child my parents were left to get on with it. After my parents died, people assumed I was able to do everything for myself, even though for over 40 years I heavily depended on them."
>
> *A young stroke survivor, now middle-aged*

## Emotions experienced by parents and families

“It’s like a form of grief - you go through all the stages – coping, denial, anger.”

*Parent of a childhood stroke survivor*

Parents describe various stages of emotional distress resulting from a child or younger person having a stroke. Initial shock and panic caused by the stroke itself is heightened by the general lack of awareness that strokes can occur at any age. Many parents find they pour all their energy into ensuring their child receives the best treatment and care. Anxiety and depression can hit later when longer term effects of the stroke become apparent.

“Was it our fault, was it genetic, was it because of an accident we didn’t prevent? There was an internal struggle of guilt. Was there something we could have done?”

*Parent of a young stroke survivor*

Many parents blame themselves for their child having a stroke, and are anxious that they will have another one.

There is often a tension between wanting to protect their child and at the same time allowing them to become more independent. Parents can also have concerns about their child’s future and how they will deal with any ongoing effects of a stroke as they progress into adulthood.

“I am terrified about if they go out drinking, or try smoking like teenagers can do – there are just so many extra risks. When they are older will they be able to get life assurance or loans; will it have an impact on job prospects?”

*Parent of a young stroke survivor*

“Other people didn’t really understand or believe that my child had had a stroke, especially as they look ‘normal’. They’re very sporty; people say they look fine.”

*Parent of a young stroke survivor*

Parents experience frustration when others do not understand the “hidden” effects of the stroke, such as the emotional consequences. Some parents report a low level of professional understanding of stroke in children and younger people and issues with awareness of the impact of stroke in schools. There are some excellent professionals out there, but we would like to see all younger people who need specialist support being able to access it.

Siblings are also affected. They can feel neglected while parents are focused on the stroke survivor, or confused about what has happened and what changes they may see in their brother or sister.

## What help is available to support younger stroke survivors and their families?

Parents report a lack of information and advice about stroke in children and younger people. Others comment on the lack of stroke support services specifically tailored for younger stroke survivors and their families.

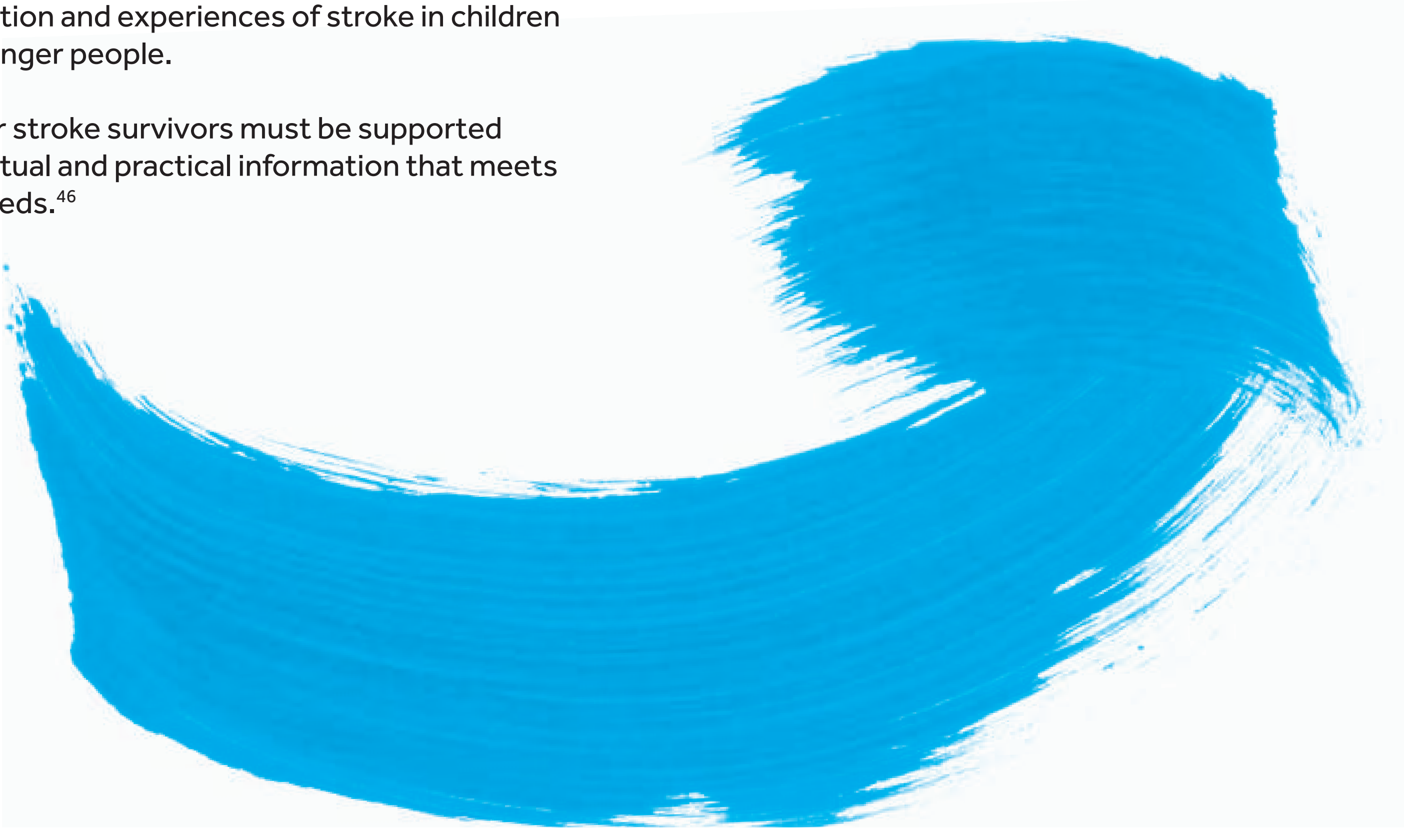
> "Just knowing there is a place you can go, where people know what you have been through and where you can get advice, is so important."
>
> *Parent of a young stroke survivor*

Many parents emphasise the importance of peer support. One parent we spoke to created the *My Child had a Stroke* Facebook group to help parents connect with each other and share information and experiences of stroke in children and younger people.

Younger stroke survivors must be supported with factual and practical information that meets their needs.[46]

> "I am a young stroke survivor and feel that there is not much available for me in terms of support. It has taken a year to be referred to a wellbeing counsellor about my fear of having another stroke."
>
> *A young stroke survivor*

***Stroke Survivors' Declaration* point three:**
When I go home from hospital I will have specialist support.[47]



# The Stroke Association and The Evelina Children's Hospital Childhood Stroke Project

Working with the Evelina Children's Hospital in London, the Stroke Association is developing the UK's first dedicated childhood stroke community support service as part of a three year project. This will give children and their families in London, and the South East of England the long-term support they need after a child has had a stroke.[48]

The childhood stroke coordinator will work with health professionals to raise awareness of childhood stroke and produce new information materials.

The service also aims to create a network for families affected by childhood stroke, enabling them to meet, forge bonds and create friendships with one another so that they can reach out and support each other, something that many parents of young stroke survivors have reported would have been useful to them.

We are hopeful that the learning from this project may provide a template for helping younger stroke survivors across the UK and will establish cost effectiveness of investing in these vitally needed services.

**Call to action for those who plan and provide health and social care**

Support children and younger stroke survivors from diagnosis, through sign-posting to peer support groups and ensuring a seamless transition to adult services. This must include more effective assessment and treatment of the emotional and psychological impact of stroke on children and younger stroke survivors and their families.

# Joanne's story

**Joanne led a full and busy life, working with vulnerable adults as well as being mum to two boys. But one day she felt her sight "go funny" and went to her optician. It was only seven months later she learned she'd had a stroke. Two and a half years after that, she had a second stroke.**

Then her life started to crumble. Joanne had to give up work. And the dynamic in the house changed. "I'm sure that because I looked fine, and there was no diagnosis, family and friends just couldn't believe I was ill. It was hard to explain and hard for them to adjust." Her relationship with her husband became strained and they split up for three months.

Joanne felt so emotional all the time, often crying, and if she had a bad day she'd find it hard to bounce back. "There was no in-between; it was all extremes. With the damage to my brain if something upsets me there's no cut off point."

Joanne's second stroke was diagnosed immediately and she was in hospital for ten days. Once she'd left the hospital, the only support she had was from her occupational therapist, but this had to end after a year, even though that's when Joanne really needed someone.

"I do now get counselling to help me cope with my depression though. Everything needs to be written down for me or I forget. And I'm only recently learning to say no to things, to cancel appointments if I haven't got the energy. I do hate to let people down but sometimes I just don't have the stamina and not many people understand that."

The Stroke Association also helped. "They explained why I was tired all the time, why I kept going into the kitchen and leaving the gas on. It only made sense once I knew what a stroke meant and what damage had happened to my brain. They also met with my husband, and that helped a lot.

"Having information about stroke earlier would definitely have prevented the split from my husband; and it's only because of my Stroke Association worker that we are all now back together as a family."

"I kept going into the kitchen and leaving the gas on. It only made sense once I knew what a stroke meant and what damage had happened to my brain."

“I’m sure that because I looked fine, and there was no diagnosis, family and friends just couldn’t believe I was ill. It was hard to explain and hard for them to adjust.”

# Timely information, practical advice and support is essential

## Stroke survivors, their carers and families need support in understanding what has happened to them.

> "I am a new, inexperienced carer just trying to do what I can. I haven't had much time to think about what help there may be or what questions to ask."
>
> *A carer*

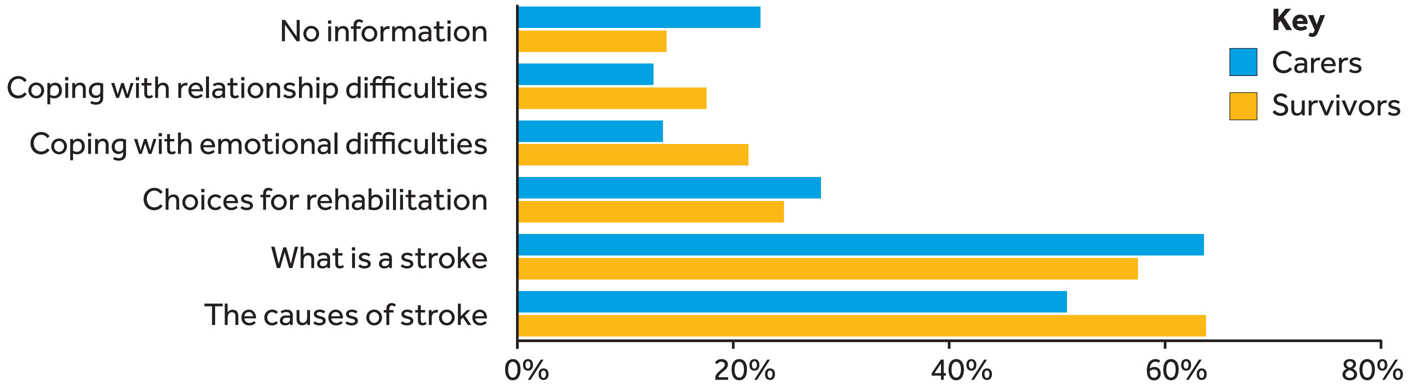
A stroke can change everything, however with help families can better manage the situation and plan for the future with realistic expectations. Many people tell us they are relieved to hear that the after effects they are experiencing are normal, and indeed to be expected.

Sometimes the effects of stroke can seem frightening and embarrassing, such as problems with intimacy, sex and incontinence.[49] We believe all stroke survivors and carers must have access to quality information and advice, in a format they understand and at a time that works for them, in order to enable them to make their best recovery.

While the majority of the stroke survivors who participated in our survey had received information about stroke, few had received information, practical advice or support about coping with emotional and relationship difficulties following stroke.

Our latest findings chime with those of our previous surveys, where over a quarter of stroke survivors were not aware of sources of free information and support.[50]

## What information and advice people say they received after stroke



> "Being given lists of useful links and phone numbers is no use when we are not able to take in the information, can't summon up courage to phone, don't know where to start. Don't wait for us to phone up."
>
> *A stroke survivor*

Stroke survivors told us if they did receive information, it was often during the early stages of recovery, at a time when they had difficulties understanding it because of the enormity of what had happened them.

Too often the information given did not mention the emotional impact of stroke and where they could seek help. Some mentioned they received good support from GPs, but others said that they were offered little help.

> "When I was discharged I was left to research my stroke myself. GPs were only concerned with feeding me tablets. No one discussed my weight or diet. I now pay for a private doctor and I'm very happy."
>
> *A stroke survivor*

## Carers feel overlooked and unappreciated

When asked to tell us about their experience many carers said they were never asked if they wanted to be the carer, it was simply assumed they would take this role on. Too often their wishes were not taken into consideration, and their knowledge of the survivor was not respected.

Most carers would have appreciated information, practical advice and support about the emotional effects of stroke. Many carers felt they lacked training and peer support which would have been really useful. They often had their own, different questions that they needed answering.

**Call to action for those who plan and provide health and social care**

Ensure all stroke survivors, their carers and families are given accurate, timely, and accessible information at all stages of their stroke journey to help them adjust to the emotional impact of stroke.

***Stroke Survivors' Declaration* point six:**
I will be given the information and advice I need, in the format I need.[51]

# Eleanor's story

**Eleanor was driving when all of a sudden she felt as if she was drunk, so she stopped and got out of the car. Moments later she fell to the ground. Eleven hours and two hospitals later, Eleanor was diagnosed with a stroke. Doctors told her family she had six hours to live.**

Eleanor was in intensive care for seven weeks, during which time she could do nothing but move her eyes. It was a terrifying experience. And yet, she felt safe in the hospital, being cared for.

The "nightmare" began after she left hospital and had to rely on community services. "The stroke meant that I couldn't work. It took weeks before I received any help applying for benefits."

"My balance was all wrong; I always felt so tired, and I couldn't eat or drink, so just having a coffee and catching up with friends was hard." Eleanor's parents didn't know what to do to help. It was only when they got in touch with the Stroke Association, who listened and gave advice, that they felt more confident supporting their daughter. "Even now we still have to work at keeping ourselves together, because the stroke changed everything."

Eleanor is grateful for the medical help she had in hospital, but it's been the emotional journey that's been the biggest battle. "The team in the hospital saved my life. But it was the rehabilitation team that made my life worth living."

Eleanor's parents didn't know what to do to help. It was only when they got in touch with the Stroke Association, who listened and gave advice, that they felt more confident supporting their daughter.

Eleanor is grateful for the medical help she had in hospital, but it’s been the emotional journey that’s been the biggest battle.

# What stroke survivors and carers need

Regular assessments and reviews are vital for stroke survivors and carers.

> "If I am to be assessed I want it to be someone who understands stroke and all the after effects if you are lucky enough to survive in the first place."
>
> *A stroke survivor*

## Emotional and physical health assessments

While the format differs across the UK, stroke survivors should be offered regular reviews of their health and social care needs. However, studies have shown that too many stroke survivors and carers are not receiving these reviews.[52] Reviews are vital as they are an opportunity for emotional and physical issues to be identified before they develop into something more serious. This is particularly important for people whose strokes occurred a number of years ago and may no longer be on the stroke pathway.

It is important that stroke survivors are supported by professionals and care staff who are knowledgeable about stroke and fully understand its impacts.[53] More than eight in ten stroke survivors say people they came into contact with after their stroke did not understand stroke and its impact.[54]

Feedback from people who use Stroke Association services demonstrates how much stroke survivors and carers appreciate working with people who understand stroke and the complexity of its effects.

We know that survivors treated by stroke specialists and other professionals with relevant stroke knowledge and skills are more likely to survive stroke, return home and become independent.[55]

As well as national plans and strategies for stroke, best practice recommends that all health and social care staff in direct contact with survivors and carers should have a broad understanding of stroke.[56] Those responsible for developing services should consider the additional needs of those living with aphasia, and professionals should support survivors with aphasia to access services.

## Clinical psychologists are a vital part of the team

> "The Acute Stroke Unit gave excellent 'physical' care, but no one seemed able to offer emotional help or was aware that it may be needed. All people in the ward were frightened. The nursing staff knew how we felt, but didn't openly acknowledge that fear."
>
> *A stroke survivor*

Multi-disciplinary teams (MDTs) and those who plan and provide services should already consider emotional support as being as crucial to recovery as physical rehabilitation.[57] We believe increased investment in clinical psychology is vital.

Work by the NHS Stroke Improvement Programme (in England) indicates that an investment of around £69,000 in psychological care through a clinical psychologist-led service, with clinical psychology assistant support and an appropriately trained multi-disciplinary team, may deliver a benefit of around £108,000 to the NHS and social care in around two years.[58]

The Stepped Care Model [59] is one way of supporting stroke survivors to deal with the emotional impact of stroke:

- Level 1 involves providing stroke survivors with education about the natural process of psychological adjustment following stroke and education regarding cognitive problems.
- Level 2 is a more intensive level of intervention to manage mild to moderate psychological needs but can be carried out by non-psychology staff, by stroke-specialist staff who have had training from a clinical neuropsychologist and have access to supervision from them.
- Level 3 is designed for individuals who have more severe and complex psychological and cognitive problems.

In the North West of England, Stroke Association Information, Advice and Support Coordinators attend meetings with clinical psychologists. Our staff will work with people at the lower level of the Stepped Care Model, some of whom are on a waiting list to see the psychology team. By the time some of them reach the front of the waiting list their issues have been resolved by our staff, saving clinical psychologists unnecessary work.

> "I finally am seeing a psychologist to help with my problems, but the amount of time taken to get rehab has left me in a state that cannot easily be gotten out of."
>
> *A stroke survivor*

## Promoting better understanding of stroke

In writing this report we spoke to many health and social care professionals and heard of lots of innovative work delivering better outcomes. However despite pockets of good, some healthcare staff have reported avoiding talking to a visibly upset stroke survivor to avoid opening a can of worms. To help with this we have produced a leaflet called *You're not alone: coping with the emotional effects of stroke - a practical guide for stroke survivors and carers*, which we hope may provide a useful support and starting point for conversation.[60]

Over the past five years, much of the improvement in the hospital treatment of stroke has been made possible by sharing evidence and best practice. We will work with any person in health and social care who can help make this a reality.

This report shows that 40% of stroke survivors feel abandoned after leaving hospital. We now believe it is vital to collect data about what happens weeks, months or even years later to support people to get on with their lives.

If you're particularly proud of your service or the work that you're doing to help people affected by stroke please get in touch with us at **campaigns@stroke.org.uk** so we can help share your best practice with others.

***Stroke Survivors' Declaration* point five:**
I know my needs will be reassessed after 6 weeks, 6 months and/or 12 months, and as they change.[61]

### Calls to action for those who plan and provide health and social care

- Ensure all stroke survivors, their carers and families are given accurate, timely, and accessible information at all stages of their stroke journey to help them adjust to the emotional impact of stroke.
- Ensure that all stroke survivors receive a regular review of their health and social care needs that should include an assessment of their emotional and psychological wellbeing. Survivors' emotional wellbeing should also be a key part of their health and social care plans.
- Ensure all carers are aware of, and receive, a carer's assessment. This assessment should include a review of their emotional wellbeing and result in them getting the help they need.
- Ensure the monitoring and publishing of data on the long-term emotional experiences of survivors, carers and families to show if and how they are accessing emotional support, for how long, and whether their needs are met. This should look at people's experiences beyond the stroke pathway and focus on the stroke journey taken by survivors and carers.

# Abdul's story

**Dad to a ten-year-old little girl, and busy working for London's Labour Party, Abdul was busy but happy. Then one day at work he felt unwell, his words stopped coming out, and a colleague drove him to hospital. Abdul had had a stroke.**

In hospital for two weeks, Abdul felt that doctors talked about him rather than to him. "But I kept going because my family came in and gave me support."

It was only after leaving hospital that the full impact of his stroke hit him. "I couldn't walk or talk. I didn't know anything about stroke, and there wasn't much information. I relied on Stroke Association leaflets to educate me about my condition."

In some ways the stroke brought him and his daughter closer together, but he still feels guilty he was a burden at a time when he should have been supporting his family.

"My young daughter gave up things to help my recovery, to the point that I felt she'd lost years. It still kills me when I think about it."

It's taken Abdul two years to get back to any sort of normality. "I look and sound like a healthy man, and to anyone who didn't know me before, it'd be hard to imagine how bad my stroke was."

But Abdul was "very stubborn" and worked hard to regain control over his mind and body. It was this same drive that helped Abdul set up a stroke club in Newham, London. "You can't always speak to your family about how you feel; you need to know that there are others who've gone through a similar experience."

At first 11 people met once a month. But there are now two meetings a week and about 40 people attend each meeting. "People would like to go twice a week, but they cut our dial-a-cab funding."

Abdul watches members make friends and, as they become stronger and more independent, sometimes come back to support new survivors. "You can see people grow from week to week."

"People need stroke clubs for the practical and emotional support. There is only so much that medicine can do."

It was only after leaving hospital that the full impact of his stroke hit him.

> “People need stroke clubs for the practical and emotional support. There is only so much that medicine can do.”

# Support from other stroke survivors and carers

Clubs and groups offer stroke survivors and carers the opportunity to meet others and help them to make better recoveries.

> "The only ray of sunlight is that we belong to a self-help group of stroke survivors in a weekly exercise session."
>
> *A carer*

Stroke survivors and carers have told us that friendships change following a stroke and many feel alone and isolated with no one to talk to.[62] Clubs and groups offer the opportunity to meet others who have gone through a similar experience and make new friendships. Through regular meetings and a programme of activities, they invite people to come together, share experiences, regain confidence, relearn skills, and try out new things.

## What are the different types of groups and clubs?

There are over 600 stroke clubs and groups supporting people affected by stroke across the UK. Most are independent stroke charities with many choosing to affiliate to the Stroke Association. There also approximately 90 Stroke Association voluntary groups, which are run by our volunteers as part of the Stroke Association's Life After Stroke model. There are also many more groups that are not stroke specific.

Once people have joined a club or group they can remain members for as long as they need to on their stroke journey. In addition, there are other types of support available.

**Befriending –** when someone, who is usually a volunteer and often a stroke survivor, goes to visit a stroke survivor and/or their carer to offer support.

**Peer support –** where a stroke survivor supports another survivor, or a carer supports another carer.

**Group support –** a mix of befriending and peer support, but taking place in a group setting.

## Why are stroke clubs and groups important to recovery?

Once stroke survivors have left hospital and all other interventions have ended, stroke clubs are a way for people to continue receiving support.

For some people, it's the only time they get the opportunity to socialise. Particularly for those living with aphasia, it's an opportunity to build confidence by practising their communication skills in a supportive environment. Stroke survivors and carers get hope from seeing other people recover.

Clubs and groups allow people to "normalise" their experience, and hearing from people who have been through the same experience can be much more powerful than hearing from a professional.

There are opportunities to get involved in pursuits that can be therapeutic and helpful to recovery, such as art, music and exercise. Many people consider belonging to a stroke group as a way of giving back to their community, making use of skills they had when they were employed and allowing them to move on with their life.

> "Joining a stroke club gives interaction with other stroke survivors and professionals and get ideas on matters that would be of concern to you, and you can get advice."
>
> *A stroke survivor*

## What commissioners can do to support clubs and groups

Support for stroke clubs and groups by those who plan and provide health and social care is critical to the survival of this kind of community-based help.

To be considered an effective source of support and part of the stroke pathway, stroke clubs should provide high quality, and high impact long-term social and peer support. Promoting the work of clubs and groups, signposting and referring survivors and carers costs very little but can be very beneficial for the individuals concerned.

Some commissioners have made small grants available to people or organisations to allow them to set up a group or club which then becomes self-sufficient. This can result in good outcomes for survivors and carers, whilst being cost effective for service planners and providers.

> "We attend a stroke club. This used to be every Wednesday. Due to lack of funding, this is now once a fortnight, which my husband misses. We are now losing touch with friends made."
>
> *A carer*

As an example, one stroke group was given a grant of £3,100, allowing an exercise group to be created for stroke survivors. The money paid for exercise equipment, group outings to build confidence and invited guests such as neuro-physiotherapists who work with members. The group has gone on to identify the need for carer support and has secured funding from a charitable source to enable a monthly carers group to be set up.

**Call to action for those who plan and provide health and social care**

Ensure that you are promoting the work of clubs and groups and signposting and referring survivors and carers.

***Stroke Survivors' Declaration* point fourteen:** I can expect to participate in my community, either through employment or volunteering, and be supported in doing so.[63]

# Christine's story

**Christine was in her forties, working part time to finance a new business, caring for her ill father and volunteering with disabled children. "Probably doing too much, really." Then in May 2011, her world changed forever.**

Christine had a stroke caused by a blood clot in the brain.

In hospital, professionals seemed to talk about her, not to her, although Christine's still not sure if it was the after effects of the stroke that made her feel this way. All she knows is that she will be forever grateful to the nurse who comforted her when she had her breakdown.

After leaving the hospital, Christine had no support – until she found the Stroke Association. Before that, her husband, Steve, had to take time off work to care for her. He was made redundant, "probably because of the time he'd had to take off to look after me". But although this has caused other pressures, Christine's glad they're together now.

"Our relationship is even stronger now. Steve refused to leave me, even at my lowest point."

Since the stroke, Christine feels changed as person. "It's like I haven't fully come back. I've not had too much damage to my mobility, and I think that's why friends say they can't see any change; but I know I'm a different person."

She has to take things easy – dirty pots and pans have to wait. But she can't cope with the noise of the TV, the car radio or the sound of her grandchildren. Everything feels so intense. And she still has anxiety attacks and is being treated for depression.

"I can see the wood for the trees now. But if it wasn't for the Stroke Association I wouldn't have received any support at all."

In hospital, professionals seemed to talk about her, not to her, although Christine's still not sure if it was the after effects of the stroke that made her feel this way.

“I’ve not had too much damage to my mobility, and I think that’s why friends say they can’t see any change; but I know I’m a different person.”

# Ways in which the Stroke Association can help

At the Stroke Association we understand the devastating emotional impact of stroke. As you have seen in this report, the stroke journey is different for each stroke survivor and their family.

Every year nearly 40,000 stroke survivors and their families are helped by our Life After Stroke services. Stroke survivors and carers have told us of the crucial difference our services have made to their lives, even after they have left the stroke pathway and are trying to regain their best possible life. However there is still much to be done if we are to help all people affected by stroke make better recoveries.

> "I feel after stroke the home care and help dwindles away and you are left to fend for yourself. Physiotherapy stops, speech therapy stops. What happens with the long-term care?"
>
> *A carer*

We need your help to enable us to ensure that everyone affected by stroke across the UK is supported in making their best possible recovery.

> "The only support I have had since having my stroke has been from the Stroke Association. When I was in hospital the only suggestion made was to get in touch with them. I think that it is often so hard for someone who has had a stroke to access information as people are often confused or unable to go out and get information themselves."
>
> *A stroke survivor*

## Services we provide across England, Wales and Northern Ireland

### The difference our services make

Our dedicated service staff and volunteers help people to understand how to manage their stroke, we equip carers to support their love ones whilst caring for themselves, and we prevent thousands of people from having further strokes by helping them change their lifestyles.

Our services have assisted people in avoiding being unnecessarily readmitted to hospital by alerting other professionals of crises or problems that need assessing, and we continue to support thousands of stroke survivors in making their best possible recovery and regaining their lives after stroke.

> "Thank goodness for the Stroke Association. In my experience they filled the gap in information. They played a vital role."
>
> *A stroke survivor*

### Information, Advice and Support

We offer high quality evidence-based information, a listening ear, emotional support, and practical advice, all of which make a huge difference in helping stroke survivors and their families better understand what has happened.

We work alongside other health and social care professionals to make sure that stroke survivors and their families understand what their options may be, and work with others to see that the support that is needed is in place. Stroke Association coordinators will often continue to provide support through the transition from hospital to home and will stay in touch for many months, supporting carers as they adjust to their caring role and helping the stroke survivor access the support they need. When people are ready to start thinking about the future we can help them determine what they want to achieve and start to self-manage their situation.

A key part of this support is the emotional help we can offer. Our coordinators are linked into their communities and can provide timely advice and information about what is available from the wider health, social services and other voluntary organisations. We can provide information on finance and benefits along with opportunities to access support groups and peer support activities.

If you are responsible for planning health or social care services and want to help stroke survivors and carers we would love to talk to you. Please email us at **campaigns@stroke.org.uk**. We have a range of paid for services as well as free support that can help improve outcomes and save money.

### Communication Support

Stroke survivors who are affected by aphasia have an even bigger hill to climb. Our services enable people to continue to relearn new skills of communication and to rebuild their confidence, which can be badly affected by the loss of their previous communication skills.

Our Communication Support Services complement any formal speech therapy the stroke survivor may have received. We run communication workshops to help the person living with aphasia and their carer/families to understand their condition, and offer possible solutions to the challenges they face. We cannot help people regain their speech but we can help them adjust.

Aphasia is a very isolating condition and it is critical that people are supported to engage with normal activities. So, as well as running group workshops, we work with individuals to establish what they want to be able to achieve, and we have a team of experienced volunteers who can support people to undertake those activities. For some, this may be expressing their feelings through art or gardening, learning how to shop independently, or travelling on public transport with confidence in spite of the disability. It could be we help the person's employers understand their challenges so they can return to their employment.

Where need is identified, we can create peer support groups which help people adjust and rebuild their self-worth and confidence. Our approach is one of integration across services and communities.

### Carer Support

Carer support is a key element of our services. Being a carer can be difficult and relationships are often affected. Our services help carers to identify their needs and try to ensure that these are met. It is critical that carers feel supported and have opportunities to talk or seek respite, so they can continue caring without their own health suffering adversely.

Our initial home/hospital visit is often with the families as the stroke survivor's needs are addressed by the stroke team. We can focus on helping the families understand what is happening or will happen next, and also help them be clear about decisions they may need to take together, before the stroke survivor leaves hospital.

Adjusting to life back home can be as traumatic for the carer as it is for the stroke survivor they care for. Knowing we can be on hand to offer a listening ear, emotional support, practical advice and information can help carers to cope where otherwise they may feel isolated and overwhelmed.

### Stroke Prevention

All of our service users are provided with stroke prevention support and advice as part of the package we offer. We can also provide bespoke services, where we work with people identified as at high risk of primary or secondary stroke. We offer group and one to one activities which enable people to understand their personal risk factors and take positives steps to adjust their lifestyles to reduce their stroke risk.

People tell us that these specialist prevention services make a big difference to their lives and the lives of those close to them.

## Other support we provide

**You're not alone** is a practical guide for stroke survivors and carers which offers advice on how to cope with the emotional impact of stroke. You can download this from **stroke.org.uk/feeling-overwhelmed**

**High quality information** is essential in the aftermath of a stroke. We have a range of information leaflets covering everything from what a stroke is to what's likely to happen in the future and how to live with the changes.
All of our leaflets are available at **stroke.org.uk/information/resource-library**.

**Our Stroke Helpline** (**0303 3033 100**) is open Monday to Friday, from 9am to 5pm. Each year we support over 20,000 people. We also have a language line to translate for people who don't speak English as a first language.

**Our Stroke Information Service** is also available by email on **info@stroke.org.uk**. We ask people to include their postcode so we can direct them to local support where it's available.

**Stroke clubs and groups** are a fantastic way for stroke survivors and carers to get help and support from others who have had similar experiences. To see if there are stroke clubs or groups in a particular area please call our Stroke Helpline on **0303 3033 100** or search on our website at **stroke.org.uk/support/search**.

We offer volunteering opportunities for those who would like to help support stroke survivors, their families and their carers in these clubs, groups and services. We can help people to set up stroke clubs in their local area and can also offer speakers to come and talk to your group.

**Our Talkstroke online community** is a place for people to meet, share stories and experiences and support others affected by stroke. Go to **stroke.org.uk/talkstroke**. If you are online you may also want to look us up on Facebook and Twitter for more information and support.

**The Campaigners' Network** supporters receive regular email newsletters with interesting news, personal stories and small things they can do to improve the lives of all those touched by stroke. You can sign up at **stroke.org.uk/campaigns/signup**.

## Other sources of help

**If you are experiencing relationship problems** you can contact RELATE on 0300 100 123

**If you want more information about childhood stroke** you can refer to our website **stroke.org.uk/involved/childhood-stroke**.
You can also contact **hemihelp.org.uk**, **differentstrokes.co.uk** and **scyss.org**.
There is also a Facebook group for parents of childhood stroke survivors called *My child had a Stroke*

**If you want more information about aphasia** you can refer to **stroke.org.uk/aphasia**

# Endnotes

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[24] Sentinel Stroke National Audit Programme (SSNAP) (2012) *Acute organisational audit report*.

[25] The Scottish Government (2009) *Better Heart Disease and Stroke Care Action Plan*

[26] Stroke Association (2012) *Struggling to recover*

[27] For more information about aphasia and communication difficulties please go to pages 26-29

[28] National Audit Office (2005) *Reducing brain damage: Faster access to better stroke care*

[29] Stroke Association (2012) *Struggling to recover*

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[33] RCP (2012). National clinical guideline for stroke - fourth edition

[34] Brunel University (2012). Hanging onto and hanging out with friends: experiences of friendship after stroke and aphasia

[35] stroke.org.uk/get-involved/stroke-survivors-declarations

[36] Stroke survivors with aphasia have trouble communicating and may be unable able to speak, understand, read or write.

[37] Intercollegiate Stroke Working Party (2012). National clinical guideline for stroke, 4th edition. London: Royal College of Physicians P97

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[39] Kontou (2009). Depression and aphasia after stroke: a thesis

[40] stroke.org.uk/get-involved/stroke-survivors-declarations

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[48] This project has been made possible by funding from city trading firm, ICAP, whose Charity Day in December 2012 raised over £11 million for good causes.

[49] We have leaflets available on all of these topics that are free to download at stroke.org.uk/information/resource-library

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[59] Based on Hall, V. at improvement.nhs.uk/stroke/Psychologicalcareafterstroke/Stepped.aspx

[60] Available at stroke.org.uk/feeling-overwhelmed

[61] stroke.org.uk/get-involved/stroke-survivors-declarations

[62] For more information about how relationships, families and friendships are affected by stroke please see pages 22 and 23.

[63] stroke.org.uk/get-involved/stroke-survivors-declarations

[64] stroke.org.uk/feeling-overwhelmed

# About the data in this report

We are presenting this data as a snapshot, it's not representative but it is a large sample size which we believe gives a useful insight into the real-life experience of stroke survivors and their carers. All data referred to in the report is UK-wide, national breakdowns can be found on our website.[64] Quotes used throughout the report from stroke survivors and carers are taken from the "In Your Own Words" section that was part of this survey.

## Purpose

In 2012 we ran a survey to understand the emotional impact of stroke on survivors, carers and their families.

## Methods

The UK-wide impact of stroke survey ran from October to December 2012 and was aimed at stroke survivors and their carers who each had a separate section to answer. The survey was both online (via Survey Monkey) and paper-based. The survey questions covered questions about the physical, cognitive, emotional and practical impact of stroke.

## Sample

The total sample size is 2,711, of which 1,765 people completed the paper-based version and 946 completed it online. A total of 1,774 stroke survivors responded to their section of the survey and 937 carers completed the section designed for them.

Find out more at **stroke.org.uk/feeling-overwhelmed**

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Throughout this briefing, data is mentioned from the impact of stroke survey; data tables are available online at **stroke.org.uk/feeling-overwhelmed**.

You will also find national policy calls for the four UK nations and a detailed bibliography here.

## We are the Stroke Association

We believe in life after stroke. That's why we support stroke survivors to make the best recovery they can. It's why we campaign for better stroke care. And it's why we fund research into finding new treatments and ways of preventing stroke.

**We're here for you. If you'd like to know more please get in touch.**

**Stroke Helpline:** 0303 3033 100
**Website:** stroke.org.uk
**Email:** info@stroke.org.uk
**From a textphone:** 18001 0303 3033 100

## The Life After Stroke Campaign

### Helping more stroke survivors and carers achieve a better life after stroke

Help make this happen, get involved at:
**stroke.org.uk/campaigns/signup** or **#lifeafterstroke**

Facebook - Stroke Association
Twitter @TheStrokeAssoc

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