

Sue Ryder Care is the leading voluntary provider of specialist palliative and neurological care in the UK. It operates hospices, neurological care centres, homecare and community based care services across the country.

Its vision – ‘Care that liberates lives’ – means that the charity cares for all of a person’s needs be they physical, emotional, psychological or spiritual, and is dedicated to helping people get the best from their lives, living with chronic and terminal conditions and illnesses.

Sue Ryder Care’s specialist palliative care services are based around consultant led inpatient units and comprise day hospice facilities, specialist community nurses, social work and bereavement services, which integrate with the NHS and other organisations, including oncology units, GPs and social services.

Its neurological care services provide specialised long term care and support for people with conditions including Multiple Sclerosis, Stroke, Parkinson’s Disease, Motor Neurone Disease, Huntington’s Disease, Brain Injury and Dementia, with most centres recognised as preferred providers of respite care by the MS Society. Admission is based on referral by NHS or social services and individual assessment by the charity.

All Sue Ryder Care services are free at the point of delivery and are funded through a combination of statutory funding and voluntary donations.

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Filling the Void:

How real life health information builds better services

July 2007



'Reliable health data and statistics are the foundation of health policies, strategies, evaluation and monitoring. Evidence is also the foundation for sound health information for the general public...

I regard the generation and use of health information as the most urgent need.'

DR MARGARET CHANG

DIRECTOR GENERAL OF WORLD HEALTH ORGANISATION 2007¹

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Our Vision:
Care that liberates lives

Our Mission:
To be first choice in both neurological and palliative care

¹Dr Margaret Chang, Director General of World Health Organisation. 2007. Address to the Sixtieth World Health Assembly. [Internet]. Available from <http://www.who.int/dg/speeches/2007/150507/en/index.html>

1. Introduction

Sue Ryder Care is the leading provider of specialist palliative and neurological care in the UK. The charity provides care and support from post-acute stage to the end of a person's life through community based care, home care, rehabilitation, residential care, short term palliative care and end of life care services for people living with conditions including:

- Cancer
- Multiple Sclerosis
- Stroke
- Parkinson's Disease
- Motor Neurone Disease
- Huntington's Disease
- Brain Injury

Through substantial experience working with the statutory services Sue Ryder Care has identified that one of the major barriers to ensuring appropriate and effective care and support services for all is a lack of comprehensive data reflecting the real needs of individuals and communities, particularly in the case of neurological conditions.

Sue Ryder Care has established a Health Informatics Team and has completed a Market Analysis Project (MAP). The purpose is to establish the need and demand for specialist palliative and neurological care services set against the current and planned level of service provision.

It is recognised that information collection and use is more developed in palliative care than neurological care, due in the main to mandatory cancer registries and their establishment through funds attached to the Cancer Plan².

Real life health information is crucial – for the charity and for other service providers as well as for commissioners and government in shaping future service delivery tailored to evidenced local need.

This report details key findings from nationwide research with recommendations for developing better information and more responsive and efficient services in the future.

2. Methodology

The Sue Ryder Care Health Informatics Team comprises professionals with a variety of skills and experience in data mining, statistics, analysis and presentation. The project involved a comprehensive literature search in neurological, palliative and end of life care followed by research involving a triangulation of methods. Three main forms of secondary data were collated in each geographical area:

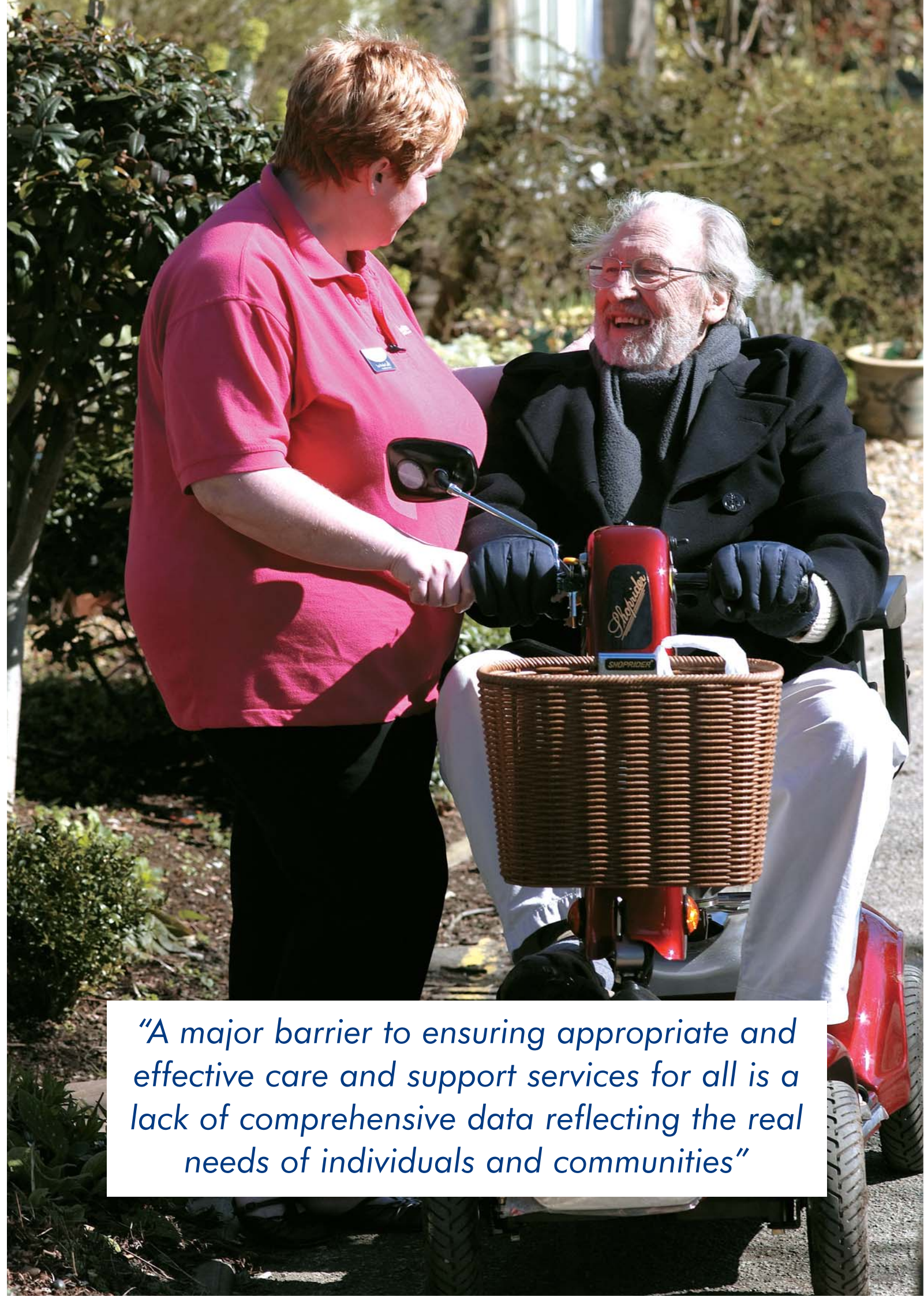
- Demographic statistics
- Strategic documents
- Structured information from key stakeholders

The data and information collected was cross-referenced and analysed. A detailed report has been produced about each Strategic Health Authority in England, each Health Board in Scotland and a summary report for Wales and Northern Ireland.

3. Early successes

Where Sue Ryder Care has already applied its Health Informatics learning, it has achieved successes including:

- Informing decisions with partner organisations for the re-development of neurological services in North West England and in North East Scotland.
- Opening discussions for the future development of services with PCTs and Health Boards. The intelligence provides a credible evidence base and supports current knowledge to identify new development areas.
- The discovery of populations requiring services previously unknown to local commissioners. For example the research enabled Sue Ryder Care to inform a Health Board that 70 people with a diagnosis of Huntington's disease were resident in their locality. Without this information these people would not be considered in local service planning.
- Informing the development of an area-wide neuro-rehabilitation service in Tayside, and acting as a focus in commissioning decisions on the future of a centre in Borders.



“A major barrier to ensuring appropriate and effective care and support services for all is a lack of comprehensive data reflecting the real needs of individuals and communities”

- The research has provided a more complete geographical picture of the gaps in palliative provision, in particular the need associated with non-malignant conditions. This is enabling Sue Ryder Care to complete a rigorous needs assessment that builds on initial palliative needs assessments by including other demographic variables.

4. Policy Context

Sue Ryder Care's experience is reinforced by recent reports from the Department of Health.

Modern commissioning is defined in 'Health Reform England: Update and Commissioning Framework' (2006)³ as:

'The means by which we secure the best value for patients and tax payers. By best value we mean:

- The best possible health outcomes, including reducing inequalities
- The best possible healthcare
- Within the resources made available to the taxpayer'

Sue Ryder Care believes that this aim cannot be achieved unless commissioners properly collect and utilise current data about the communities they serve. Evidence from the Market Analysis Project shows that commissioners are inconsistent in their approach to data, neither valuing nor respecting it.

In 'The State of Social Care in England, 2005-2006'⁴ the following failures in commissioning were noted. Sue Ryder Care believes effective data is paramount to resolving these issues, and the findings concur with those of the charity:

- Commissioners take an over simplistic cost and volume approach, focusing on outputs rather than outcomes, with a resultant lack of commissioning for quality
- Waiting times are seen as the main control on demand
- Practice is highly variable and fragmented
- There is limited use of market analysis and development

It is Sue Ryder Care's experience that in both palliative and neurological care there is a disconnect between the Government's laudable intent to develop services by policy, targets and guidelines and the delivery of those services on the ground. Local services are shaped by providers who are broadly required to respond to hard targets and mandates and commissioners who focus primarily on cost.

4.1 National targets

Currently there are no mandatory targets, penalties or funding incentives to encourage commissioners to prioritise the implementation of guidelines such as the National Service Framework for Long Term Conditions⁵ or the NICE Guidelines on Supportive and Palliative Care⁶, which would substantially improve the lives of those affected.

There are a large number of government targets aimed at improving the performance of services for people with a range of health related issues, for which managers are responsible, including:

- Waiting times
- Finance targets
- Acute episode targets
- Emergency admissions
- Clinical standards

For example, we know that 290,000 cataract operations and 85,000 hip replacements were delivered against government targets last year.⁷

However, information is not collected about the details of approximately three million people in the UK with high dependency progressive neurological conditions, including those living with Multiple Sclerosis, Stroke, Parkinson's Disease, Motor Neurone Disease, Huntington's Disease and Brain Injury. Consequently there are no tangible targets or measures for success for which managers are held to account.

Sue Ryder Care feels that it is indefensible that the life chances of people living with long term neurological conditions are decreased simply because targets and ring fenced funding are not allocated – even though they are prioritised areas through Government policy.

4.2 Current Palliative Care Initiatives

Sue Ryder Care recognises the intent of government to improve the situation around the lack of information in palliative care, most notably the recently announced baseline review for end of life services. While Sue Ryder Care welcomes this initiative it is concerned that the data collected will not be standardised or constitute a regular long term commitment to ongoing work. As such the information may be limited in use.

4.3 Partnerships with the Third Sector

Third Sector providers of care work with disparate and often antiquated funding practices. This results in a substantial shortfall between the cost commissioners are prepared to pay for the services they wish to commission, and the true cost of providing that care service. The issue is particularly pressing in that currently 80% of palliative care in Britain is provided by the voluntary sector, saving the Government an estimated £200 million per year.

Through its 'We Care: Who Pays?' campaign Sue Ryder Care is working in partnership with Government and local commissioners to improve and develop transparent commissioning practices that will bring long term benefits to communities and efficiencies to the state, as outlined by National Audit Office report: 'Working with the Third Sector'⁸ and the Gershon Review⁹.

Nationally the consequences of this continued under funding are:

- Palliative care services are being eroded. In particular statutory under funding of core services such as inpatient units, means that invaluable additional services are in danger as voluntary funds are diverted from community based services to prop up statutory shortfalls.
- Services cannot be developed effectively to meet the challenges outlined in the Health White Paper

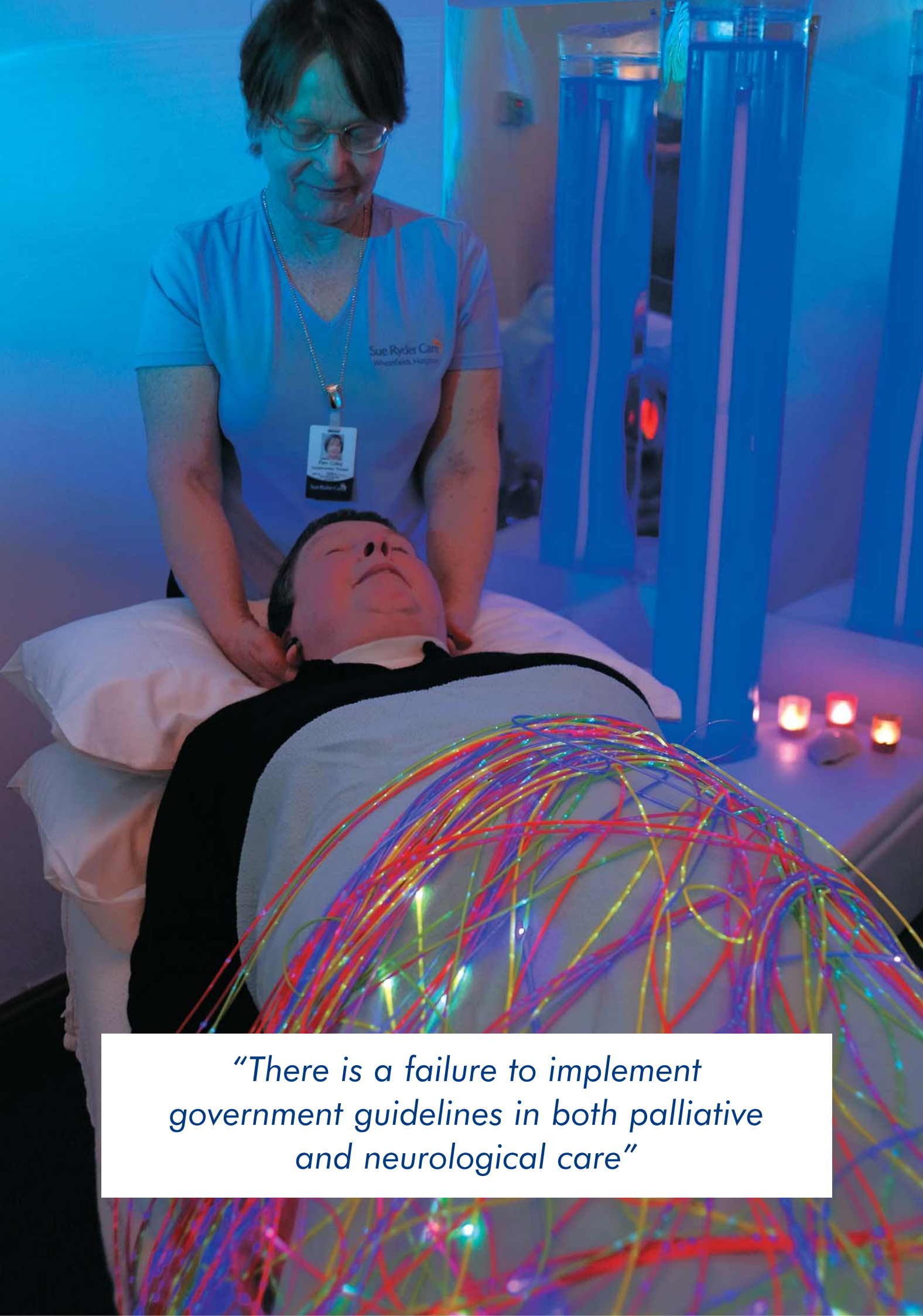
'Our Health, Our Care, Our Say'¹⁰, since valuable voluntary funds are instead used to cover shortfalls in statutory funding, and so cannot be used to develop new and innovative services.

- Planning efficient, effective services that meet the real needs of communities over time is impossible since funding is still negotiated on a year-by-year basis.
- The lack of transparency through the funding process and a nationally recognised tariff means that services are funded differently by different PCTs – a major contributor to inconsistent commissioning practices.
- In many parts of the country funding arrangements have no link to the individual being cared for, the treatment required or level of need in a community and are simply based on the grant received the previous year.

In December 2006 the 'Partnerships in Public Services: Third Sector Action Plan' report by the Cabinet Office/Office of the Third Sector (2006)¹¹ was published to reinforce the Government's intention to partner the Voluntary Sector. It once again recognised the need for statutory commissioners to fund the true cost of care received from voluntary providers, and for equitable and transparent contracting already outlined in documents such as:

- 'Cross Cutting Review: Role of the Voluntary and Community Sector in Service Delivery' HM Treasury¹²
- 'Working with the Third Sector' National Audit Office¹³
- The Compact Plus (2005)¹⁴ Home Office
- 'Working with the Third Sector' Public Accounts Committee Report¹⁵
- 'No Excuses – Step Forward Into Action' Department of Health Report of the Third Sector Task Force¹⁶

The Department of Health White Paper 'Our health, our care, our say' (2006)¹⁷ states the necessity for greater engagement with Third Sector organisations to deliver the government's vision for care and support services in the future.



“There is a failure to implement government guidelines in both palliative and neurological care”

There is a clear need illustrated through the Market Analysis Project for the development of increased services for people with palliative and neurological conditions. While pockets of excellence exist, the research demonstrates that data is not uniform across the UK making it difficult to offer a nationwide picture of need beyond that found in localities. The major challenge is moving beyond the current data wasteland.

In palliative and neurological care, Sue Ryder Care possesses the skills, experience, expertise and knowledge to play a key role in developing and operating services that meet the genuine needs of individuals and communities, in partnership with the state.

Beyond this, the charity has the knowledge and capacity to work to develop research, data and evidence, through projects like MAP, which will prove essential to developing future services that will be demonstrably responsive, efficient and outcome focused.

This potential will only be fully realised if the state, through local commissioners, pays the true cost for the care it commissions, enabling the charity to use its voluntary funds for the use it is intended and not plugging shortfalls in statutory funding.

4.4 Payment by Results

Currently the transparency offered through the commissioning process by tariff pricing as used in some areas of care, is not afforded to palliative or post-acute neurological care. Sue Ryder Care believes this operates as a disincentive to Third Sector providers of care.

Services outside the scope of practice based commissioning in 2007/08 include community services, critical care, continuing/intermediate care, respite care and rehabilitation in a discrete rehabilitation ward or unit. In addition to this, the following services are among those excluded from the outpatient tariff as specialised services; neurosurgery, palliative medicine and neurology.

Organisations are being encouraged to ‘unbundle’ rehabilitation pathways in order to encourage provision in non-acute settings. Admitted patient care mandatory tariffs are in place for elective and non-elective spells for many procedures and conditions including MS, epilepsy, brain injury and MND.

5. Findings and evidence

Efficient and effective commissioning is key to providing the health and social care services that people require. Sue Ryder Care has identified that a major barrier to providing and planning care that meets people’s real needs is that many commissioners do not possess or use the right information about their communities on which to base their decisions.

As a result people in the UK living with conditions including Cancer, Multiple Sclerosis, Stroke, Motor Neurone Disease, Huntington’s Disease and Brain Injury are not receiving the individual care and support they need.

To help the Government and local commissioners to improve and develop services, the Sue Ryder Care Health Informatics Team has conducted national in-depth research looking at the care people require in each Strategic Health Authority in the UK. It has revealed that critical information was not found, used or made available.

Sue Ryder Care has found evidence that local commissioning bodies are inconsistent in their use of data. When challenged they were unable to provide reliable, valid and current information about their communities on which to base their decisions about the provision of care for neurological conditions.

5.1 There is a failure to implement government guidelines in both palliative and neurological care.

42% of the responding Strategic Health Authorities (SHAs) showed no evidence of having a National Service Framework (NSF) for Long Term Conditions¹⁸ Implementation Team. None of the SHAs were able

to provide details of the proportion of people who had received an integrated assessment or personal care plan since the NSF launch.

Evidence taken from a survey of Sue Ryder Care Palliative Care Service Managers showed that NICE Guidelines¹⁹ on supportive and palliative care:

- are not being universally adopted
- have not been evaluated with regard to outcomes
- have not been fully implemented. For example, they recommend a range of core services such as bereavement support and complementary therapy, which local PCTs are not always prepared to fund.

Similar to the NSF²⁰, it is believed that much of the non-acceptance is due to the fact that the guidelines are just that: there are no targets, funding or penalties to ensure the guidelines are implemented.

Qualitative evidence collated from commissioners showed the lack of progress is due largely to the absence of hard targets, sanctions or attached funding. The result is that other areas of activity are prioritised.

Even where evidence of implementation exists, this was hard to find. Sue Ryder Care found in a sample of 20 PCTs in England, only seven had a required local delivery plan readily available on their website. Of these, only one mentioned the term “neurological” in the document and two mentioned the term “palliative”. Of three sample Scottish Health Boards, only one had a plan and it mentioned neither “neurological” or “palliative”. Of the three Health Board areas in Wales, the plan was available for only one.

5.2 There is a lack of strategic planning resulting in fragmented services and unnecessary spot purchasing in place across neurological and palliative care in the UK.

Sue Ryder Care has found that across the country there is a lack of consistency in the allocation of appropriate or specific planning and funds for neurological care. This means commissioning is on an ad hoc basis, which is expensive and inefficient.

Commissioners in the South West and North West of England admit that one of the main causes for their deficit is for non-contracted activity in out of county placements for continuing care.

MAP provides further evidence of inconsistent commissioning in both neurological and palliative care services. The research shows significant discrepancies between what is funded by the state, and by the Third Sector through voluntary fundraising in different localities. This is in part due to confusion as to what constitutes the statutory responsibility of commissioners for the base level of service they must provide.

An example of the continuing ‘postcode lottery’ is a Sue Ryder Care Hospice in the East of England which serves three PCTs, which all have different levels of community services and different criteria for continuing care needs. One PCT has a hospital at home service whereas another does not.

5.3 Service planning in long term neurological and palliative care is not joined up and does not take account of information earlier in the patient pathway.

One of the consequences of the successful intervention of brain injury units post-trauma is that while lives are saved, the long-term implications on continuing healthcare are not fully understood. There are costs and the need for individual support, which is often ignored by the acute services and inherited by other agencies.

Similarly, it is rare for commissioners to make the link between reducing emergency hospital admissions and the appropriate use of hospice beds.

This means that people do not receive appropriate care to meet their specific needs. Care is provided in inappropriate surroundings, either in care homes that cannot provide the level of specialist input required, or blocking beds in expensive acute units because there is nowhere else for them to go.

Simply, services have not been developed to their full potential because commissioners do not use the

information that is available across the patient pathway. Instead they operate by ‘silo purchasing’.

Patients’ needs in both palliative and neurological care are holistic. The artificial distinctions between health and social care, and acute and post-acute care make it difficult for providers to offer ‘real life’ solutions instead of piecemeal interventions.

Against a backdrop of budget difficulties the MAP found the following evidence of poor financial management:

- When budget information from each PCT was combined, seven out of ten SHAs in England show a budget deficit
- In Scotland, of the nine Boards of which financial information was available, three show a deficit
- In Northern Ireland, of the two Boards on which financial information was available, one shows a deficit
- In Wales, of the 15 Boards on which financial information was available, eight show a deficit

It is evident that neurological expenditure is not managed effectively or efficiently across health and social care locally, resulting in unnecessary expenditure and inappropriate placements.

A live example of positive change is where Sue Ryder Care has revealed that collaboration between local service providers on a joint service for people with neurological conditions in Eastern England is likely to reduce current expenditure by at least £400,000. A substantial saving of £100,000 will be realised by reducing the current number of excess bed days alone.

5.4 There is a disincentive for Third Sector providers of palliative and neurological care to develop new and innovative services that meet real needs

There is inappropriate risk sharing between Third Sector care providers and commissioners. This is in part due to the heightened financial risk of embarking on programmes where commissioners have not allocated specific budgets

nor developed strategic plans for their areas. This means that Third Sector providers develop new services at their own risk because the commissioning environment is unstable.

The situation is made worse by a lack of implementation of full cost recovery and the continuance of one year contracts. The Charity Commission reports that only 12% of charities claim to achieve full cost recovery all of the time.²¹

Sue Ryder Care finds that innovation in service delivery is nearly always provider led, rather than commissioner led. For example, Sue Ryder Care in Ipswich has developed a unique scheme to rehabilitate people living with Multiple Sclerosis. The scheme is extremely successful locally. In order to develop it in new areas the onus is on Sue Ryder Care to convince other commissioners to engage. However, to see the benefits, PCTs and local authorities would need to understand the full social and economic impact of the service across the care pathway.

5.5 Many people with long term neurological conditions requiring residential care are forced to live outside of their locality to receive appropriate care.

There is a lack of data locally to provide incentives for commissioners to develop services in their areas which would enable people to live closer to their homes and loved ones. A Sue Ryder Care neurological care centre in East of England SHA currently cares for individuals from 12 PCTs well beyond their SHA boundary.

Research shows that most commissioners could not provide financial information to show how much they spend on out-of-area care.

One of the Sue Ryder Care Centres in Scotland has 35 people on its waiting list. Currently, these patients are placed inappropriately at either a general nursing home, mental health hospital or their own homes. The cost of purchasing care from inappropriate providers, although often cheaper, can result in people being placed at risk. Sadly the

choice of location is directed by cost rather than appropriateness of care or quality.

5.6 Commissioners collect little information about people with neurological conditions in their area. The data they have is under-utilised. This makes it difficult to plan appropriate services

Disease specific organisations often collect their own, in many cases superior, information. This is not usually held in standardised formats, and consequently is not fully utilised or shared.

In the survey conducted by the Neurological Alliance in 2006 on NSF implementation²², 42% of the responding SHAs showed no evidence of having a baseline dataset of the incidence and prevalence of neurological conditions.

Standardised information is not collected regularly and therefore can only be used as a snapshot and not as a firm base for developing and commissioning services.

The situation is better in palliative care, due to financial investment through the Cancer Plan²³ and mandatory data collection through the cancer registries.

However, data on the palliative care needs of people with a non-cancer diagnosis is extremely limited.

5.7 The collation of data around diversity is an important factor when related to neurological or palliative conditions.

Commissioners could use this information to help develop services that better meet their community's needs. For example there is a link between gender and MS, ethnicity and Stroke. Sue Ryder Care found little of this information being used effectively.

When utilising demographic data, for example on ethnicity, it is important to look at local populations rather than aggregating them to SHA level. For instance, at an initial glance, the North West SHA has a smaller percentage of population who are non-white than England overall. However, there are areas whose ethnic diversity is significantly higher than the England average, such as Greater Manchester and

Blackburn and Darwen. It is therefore important that ethnicity data is not aggregated into larger areas for commissioning purposes.

A positive example of practice was found in Northern Ireland. Evidence of the increased rate of head injuries amongst males is reflected in the services available in the area.

5.8 There is a clear need for more neurological and palliative care services including: respite care, rehabilitation, community services, non-malignant palliative care and out of hospice support for palliative care patients.

Sue Ryder Care has delivered evidence that has subsequently been submitted into the Department of Health's emergent End of Life Care Strategy.

In each Health Board and Strategic Health Authority across the UK, there is a need for an increase in the following services (including either expanding current provision or development of additional services):

- Rehabilitation
- Respite
- Palliative care for non-malignant conditions
- Community care or support

This data has helped inform Sue Ryder Care's planned neurological service developments in North West England and in North East Scotland.

6. Next steps

Sue Ryder Care recognises that data is paramount, with commitment to establishing a Third Sector health informatics and research working group to undertake research and audits.

Sue Ryder Care commits to undertake the following research:

- In partnership with Neurological Alliance to measure implementation of the long term conditions national service framework within Strategic Health Authorities (SHA) and to include Social Services (SS)
- To measure implementation of NICE guidelines

covering neurological conditions and palliative care within SHAs and social services

- To measure the financial and quality impacts of out of county care placements
- To measure the hidden population such as individuals who are homeless or travellers
- To build, in partnership, on existing research, for example The National Council for Palliative Care's recent guide *Population-based Needs Assessment for End of Life Care*, particularly looking at additional variables and long term conditions
- Sue Ryder Care's research will be continuous and regularly updated

7. Action Plan

Sue Ryder Care is committed to increasing its capacity to develop information and services to better serve the needs of people living with palliative and neurological conditions, in partnership with the state.

Changes at Government and commissioner level are essential to develop and utilise data to build better services. Sue Ryder Care recommends:

- A duty should be placed on commissioners to develop and publish detailed palliative and long term neurological care strategic plans showing progress towards meeting established government guidelines. This would enable providers to work more closely with commissioners to develop effective solutions.
- It should be the responsibility of commissioners to regularly collect and utilise data in a standardised format to develop an accurate picture of patient need in their locality, which can then be used as a comparator and to build an accurate national picture. Service Planning should then be evidence-based on the high quality data collected in each area
- Centralised neurological registries, including palliative care needs, should be established by condition to facilitate service planning and development, like those already in existence for Cancer. This will fill the current information void around neurological conditions
- Third Sector providers of care, because of their unique insight into communities, can play a valuable role in developing, planning and

providing services across health and social care boundaries. To achieve this they need to be appropriately funded for the statutory services they provide as outlined in The Compact²⁴ and other documents, so that vital voluntary funds can be used for developing and maintaining new and innovative services and not plugging statutory shortfalls in funding.

- The Department of Health, in consultation with the Third Sector (which provides 80% of palliative care in the UK), should develop specifications for base-level statutory service provision with regard to palliative care, and implement tariff pricing based on full cost recovery principles. This would provide transparency for commissioners as to what constitutes the service they are obligated to provide to their community, and make it possible for commissioners and providers to negotiate effectively to provide the best palliative care for all based on an equitable and effective use of state and voluntary funding.
- To meet the need for more neurological care services including respite care, rehabilitation and specialist access or neurological uses and non-malignant out of hospice support for palliative care patients will require investment. Ring-fenced funding through a national Neurological Care Plan to implement the recommendations of the NSF for Long Term Conditions²⁵ should be made available following more detailed analysis of the situation.
- Further investment in palliative care is required to grow services to meet national need so that access is available to all those who need it, in their homes, community or in hospices, in line with the Department of Health White Paper 'Our health, our care, our say' (2006)²⁶. There is an as yet unmet manifesto commitment to double the spending on palliative care and current estimates show that the state receives £200 million in 'free care' from the Third Sector. The issue of appropriate funding for palliative care should be attended to as a matter of urgency.

Footnotes

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