Sue Ryder Briefing for Westminster Hall debate on Care and Services for Older People
September 2011

We have produced this briefing to provide you with Sue Ryder’s perspective on this important topic. We have included information about what the government can do to ensure the right services are available at the right time for older people with care needs. We have also highlighted some examples of health, care and housing services that we provide for this group.

1. About us
Sue Ryder is a charitable provider of health and social care services across the UK. We care for people with long term and end of life conditions. We operate in a range of environments with community and home-based care delivery alongside our 7 hospices and 7 neurological care centres.

We work across communities with patients, their families, commissioners, GPs and other health and social care professionals. Our services span across the health and social care divide and we aim to provide solutions across the continuum of care. Many of those receiving our care are older people living with conditions such as cancer, dementia, MS, Huntington’s disease, Parkinson’s disease, brain injury or stroke.

We are funded through charitable donations, contracts with PCTs and local authorities and revenue from our network of more than 350 shops across the UK.

2. Older people and the government
The government clearly recognises the challenges faced by older people and the need to ensure that care services and the NHS can cope with the increasing demands of an ageing population. The recent Dilnot Review and Palliative Care Funding Review both outline an excellent route-map to sustainable, affordable and high quality services for older people in the future. It is critical that these are taken forward and enshrined in legislation and not kicked into the long grass as in the past.

**Personalisation:** Excellent work has also been undertaken and planned for the future to give older people more choice and control over the care they receive through personal budgets. The aim of the budgets is to ensure that individuals purchase the care they want. While we support personal budgets, we believe there is much more to personalisation than purchasing control. It involves the availability of a range of services that are responsive to each person’s needs and wishes, as you will see below.

**Integration:** Successfully integrating services, within health, but also across social care and eventually housing, transport and leisure is the biggest obstacle to quality care for older people. The complexity of these issues, and the different sections of government in charge of each one, has meant integration tends to focus on health and social care. Integration between these two alone can be complex, though the piloting of joint budgets in this area is welcome progress.

We believe the government recognises the need to integrate further and that initiatives such as the Big Society and public service reform will seek to address this. We emphasise that concerted effort must be undertaken to bring housing firmly into the ‘integration mix’.
3. Giving People the care they want, where they want it.

Personalisation is at the heart of Sue Ryder’s services. We aim to ensure that people receive the care they want, in the right environment for them. This often means finding solutions to enable them to remain in their own homes. This can include day services at a hospice or neurological care centre, home support from a community matron or respite care when their needs worsen or their family needs a break. Alternatively, it may mean finding a solution where they can remain an active part of their community from a residential, supported living or extra care setting.

Below we have highlighted a number of services to help older people with long term or end of life conditions remain in their own homes for as long as possible, and for people who are no longer able to remain at home. There are similarities in the characteristics residential and non residential services need to work effectively:

- **Partnership working:** This may be between the different agencies helping an individual to remain at home. Alternatively it may be a partnership between the charity and a housing association that enables them to live in a supported living setting where they remain at the heart of the community.

- **Flexibility:** Ensuring that the service each individual receives is designed around their wishes, whether this means supporting them to decorate their bedroom in residential care or tailoring day service activities to their particular interests (painting, crafts).

- **Progression:** The progression of services under one provider’s roof is important to the continuity of an individual’s care. This may be as an individual’s needs worsen and they move from the day hospice to an in-patient hospice bed, or it may be that an individual can move out of residential care and into supported living if their needs become less intensive.

4. Services for people living at home

Below we have highlighted two Sue Ryder services that enable people to remain in their own homes for longer, if that is their wish.

4.1 Daycare

Most of our hospices and care centres offer a range of day services. These services help with the physical, emotional and social needs that people living with long term or end of life conditions face. They play a major role in enhancing quality of life as well as helping to prevent patients reaching a crisis point that would require more acute care or permanent admission to a care home.

Day services also provide a crucial break for families and other carers without which they might not be able to continue caring for someone at home. Betty Butler, who is 67 and lives with MS, attends the neurological day centre at Sue Ryder - Thorpe Hall Hospice in Peterborough, she says starkly:

“My husband and I didn't get married so he could do my hair. It’s nice having a carer to do some things because it gives Tony a break. There was a time when I sat in a chair at home. Tony shouldn't have to sit in a chair just because I am.”

Our hospices provide a higher intensity of healthcare support. Out-patient services can include blood transfusions; ensuring a patient does not have to go to hospital to receive this kind of support.
Patients may move between our day hospice services and our in-patient hospice facilities when their needs intensify or as they near the end of their life. By this time, both the patient and their family are comfortable with their surroundings.

4.2 Community Matron Service

Many of these services are designed to realise the Department of Health’s goals as set out in the 2008 End of Life Care Strategy; echoed and developed in the recent Palliative Care Funding Review. A key aspect of which is coordinating services to ensure access to quality services and a reduction in emergency admissions.

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<th>Case Study: Community Matron Service, Nettlebed Hospice, Henley</th>
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<td>This project is a partnership between Oxfordshire PCT and Sue Ryder. The Community Matron Service helps patients to be monitored and cared for in their own homes and to access health services in the community where possible. Their case is carefully reviewed, symptoms are managed and as their condition develops appropriate palliative care is accessed. Evaluation has demonstrated a significant reduction in hospital stays and unplanned admissions realising a £64,000 saving to the PCT in 2008. It has been recognised by the Department of Health as an example of ‘making change happen’.</td>
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The community matron service works in partnership with the in-patient unit of the hospice to ensure that if the patient’s needs worsen, they can be admitted. There is a common misconception about hospices that people go there to die. In fact many are admitted to our hospices for respite for a few days to control their pain medication for example. A combination of our hospice services can enable an individual to die in their own home if that is their wish.

500,000 people die every year in the UK, most in old age. A recent Demos report\(^1\) showed 66% of people wanted to die at home but only 18% achieve this. Only 8% of people wanted to die in a hospital, but 60% currently do. If a greater range of services such as those above were commissioned then a greater number of people would be able to die at home rather than in hospital. Many admissions to hospital are unnecessary and a result of a lack of appropriate services in the home. For example, an NAO survey\(^2\) in Lincolnshire found that 68% of dementia patients in acute hospital beds were not actually in need of acute care.

5. Services for people who can no longer live at home

For some with very complex needs it is not possible to remain at home. We provide a range of services for this group. Historically these services have been provided from our residential care centres, but we recognise that people’s wishes differ, and as such, we are diversifying our ‘residential’ offering so that only those with the highest needs or those who wish to enter residential care will do so in the future. This approach takes time, but as you will see below, we are making progress.

5.1 Supported Living

As the government’s agenda moves towards keeping people in their own homes or communities for as long as possible, alternatives to residential care for those with high needs must be sought. Supported living can serve as a bridge between the home and residential care.

We are experiencing increasing demand for supported living projects from Local Authorities and it is an area we are planning to expand in the future. The key to this, and to many other integrated support models, is partnership working. There is a great deal of talk about the integration of health and social care but housing is critical to the success of integrated care. Sue Ryder has an excellent example of this in practice (below) with a partnership between the charity, local authority, PCT and a housing

\(^1\) [http://www.demos.co.uk/publications/dyingforchange](http://www.demos.co.uk/publications/dyingforchange)

association. Without this kind of partnership working and an increased stock of available housing, it is
difficult to see how the supply can meet the demand. As such an integrated strategy is needed from
government on this area to ensure that people are able to receive the care they want in an
environment which is suitable for them.

The Dilnot commission clearly recognised the enormous problems that exist around the housing
situations of elderly people in need of care. The ideal situation is people being able to stay in their
own homes but where this is not feasible alternatives are short in supply. Developing supported living
models may well be one aspect of finding solutions to this problem.

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**Case study: Bixley Road Supported Living, Ipswich**

Bixley Road is a supported living facility for those with neurological conditions and a partnership
between Sue Ryder, Progress Housing Association, the Local Authority and PCT. Four tenants
were chosen from The Chantry care home and day service who were suitable for more
independent living but still needed health and social care support 24 hours a day.

Tenants are given daily support where needed but all collaborate to play an active role in the
running of the house. The project has reduced costs for the PCT and given residents an improved
quality of life. One of the residents described the change: “I used to live in a home. Now I live at
home.”

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5.2 Extra Care

As more people live longer, often with complex multiple conditions they will need health and social
care to enable them to live as full and active lives as possible.

Heyeswood Retirement Living development in Haydock is a partnership between Arena Options
Housing Group and Sue Ryder. Heyeswood includes 92 one and two bedroom apartments as well as
communal facilities including assisted bathing, bistro, hairdressers, guest suite, IT facilities and
greenhouse. Sue Ryder have 22 carers who provide over 500 hours of round the clock care every
week at Heyeswood.

This type of extra care arrangement for elderly people makes unexpected acute admissions rare and
provides a rewarding community setting for residents. It allows families to stay together as well as
forming strong bonds through communal living with their fellow residents.

6. Dementia Services

Dementia is an ever-increasing issue for older people, and we have started to think about a range of
service solutions to fit patient’s needs. Over 750,000 people in the UK have a form of dementia⁶, a
figure set to pass a million in the next 15 years. The NHS already spends £8.2 billion a year⁴ on
dementia and people over 65 with dementia are currently using up to one quarter of hospital beds at
any one time⁵.

Dementia services must play a key role in any attempt to improve care more generally for older
people. Dementia is often found in conjunction with other conditions and is seen across Sue Ryder’s
palliative and long term neurological services. We also operate specialist dementia services.

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⁴ [Paul Burstow in Commons debate, 7 June 2011 -
http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm110607/debtext/110607-0004.htm#11060779000002](http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm110607/debtext/110607-0004.htm#11060779000002)

⁵ [All Party Parliamentary Group On Dementia Report -
6.1 Residential
Sue Ryder - Birchley Hall is a specialist residential home for people over the age of 55 and has a purpose built 10 bed EMI (Elderly Mentally Infirm) unit for people with dementia. The unit is specially adapted to serve specific needs of people with dementia and uses bright colours, special signage and pictures to aid recognition. Staff have received special dementia training to be able to support residents and rooms are designed to ensure patient recognition and to prevent them going out on their own at night.

6.2 Day Service
We also operate a Synergy Café out of Sue Ryder - The Chantry which is an open day drop in service for people with dementia and their friends, families and carers. Developed with the Alzheimer’s Society the café has trained staff on hand providing activities, education, information and practical advice. With the number of people in Suffolk affected by dementia set to rise by 65% for those aged 65 and over, the service is providing an invaluable service to patients, their families and the community.

7. Conclusion:
At the heart of the personalisation agenda is the theme that there is no one size fits all solution to the care needs of service users. As we have outlined, personalisation is made up of a range of different services working together to provide the best pathway of care for an individual, across the continuum of care. Providers like Sue Ryder work hard to ensure that the goals and aspirations of older people with long term or end of life conditions are met, regardless of the intensity of their needs.

If you would like more information on any element of this briefing, please contact Blanche Jones, Head of Public Affairs and Policy at Sue Ryder on blanche.jones@sueryder.org

6 Living Well with Dementia report, NHS Suffolk, NHS Great Yarmouth and Waveney and Suffolk County Council - http://www.suffolk.gov.uk/CareAndHealth/Advice/OlderPeople.htm