

# Health, social care and sport committee inquiry: Impact of the Social Services and Wellbeing Act (2014) on carers

## A Hospice UK and Hospices Cymru response

September 2018

### About Hospice UK

1.1 Hospice UK is the national charity for hospice care. We champion and support the work of more than 200 member organisations, which provide hospice and palliative care across the UK, so that they can deliver the highest quality of care to people with terminal or life-limiting conditions, and support their families. Our vision is hospice care for every person in need and our mission is to enable hospice care to transform the way society cares for the dying and those around them.

### About Hospices Cymru

2.1 Hospices Cymru is the collective voice of Hospice UK members in Wales. This includes the 13 adult hospices and the two children's hospices in Wales. The group seeks to advance hospice care and enable better palliative and end of life care for more people in Wales.

### About this response

2.3 We welcome the opportunity to respond to this consultation on the impact of the Social Services and Wellbeing Act (2014) on carers. This response draws on the experience of hospices in Wales supporting carers of people with terminal or life-limiting conditions, and those at the end of life. It also draws on the knowledge and experience of Hospice UK working at a national level and of academic research in the field. We have limited our comments to those issues affecting carers of people with terminal or life-limiting conditions.

### Context: carers of dying people

3.1 There is no definitive number, or robust way of working out the number of carers of people approaching the end of life, nor a consistent approach in whether numbers are based on being in the last 12 months or 6 months of life, or by having a terminal diagnosis or life-shortening condition. Estimates vary from around 500,000 to 1 million carers of dying people in the UK.<sup>1</sup> At a Wales level, this is equivalent to between 24,000 and 48,000 carers. This is based on the assumption that of the 24,000 people who die each year in Wales with a palliative care need, each one will have between one and two people caring for them.

3.2 Carers of dying people face unique challenges, including: difficulties coping with the increasingly complex and demanding needs of the person being cared for; having to coordinate care and professionals on a 24/7 basis; having conversations about resuscitation, artificial feeding and stopping treatment; and dealing with loss and grief in bereavement.

<sup>1</sup> See [http://www.ncpc.org.uk/sites/default/files/Who\\_Cares\\_Conference\\_Report.pdf](http://www.ncpc.org.uk/sites/default/files/Who_Cares_Conference_Report.pdf) and <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/december-2015/hidden-costs-of-caring.pdf>

- 3.3 For parents caring for children with life-limiting conditions, the caring journey can last several years and will impact on the person's ability to maintain employment and to sustain a family life with partners and other children.
- 3.4 The nature of caring for a person who is approaching the end of life means that the level of care needed will increase significantly throughout the caring journey. A recent academic study found that in the last three months of the decedent's life, carers contributed a median 69 hours 30 minutes of care-giving each week,<sup>2</sup> demonstrating the substantial responsibility and pressure on carers of dying people.
- 3.5 Following bereavement, the needs of carers enter a new phase that is as important as their needs while actively caring. Carers can experience a profound sense of isolation, loss of identity and loss of valued relationships with staff of services the cared-for person was using. As many as one in ten carers experience profound grief disorder (PGD) following the death of the person they cared for, which can have serious implications for their mental health.<sup>3</sup> It is therefore important to include bereavement support as part of an ongoing assessment of a carer's needs, to identify whether an early intervention from a bereavement service, including pre-bereavement support, is required.
- 3.6 The majority of carers of people with terminal and life-limiting conditions will come into contact with health services – hospices and NHS services – in the first instance. It is therefore vital that hospices and NHS services are able to identify and support carers, and to refer them to the local authority for statutory support, where this is appropriate.

## How we're supporting carers of dying people

- 4.1 With this in mind, Hospice UK is supporting the implementation of the Carer Support Needs Assessment Tool (CSNAT), a person-centred, evidence-based approach to carer assessment and support in end of life care.<sup>4</sup> Hospice UK has supported teams from over 50 hospices to be trained in the use of CSNAT. The CSNAT tool is now used internationally and has shown that assessing carers' needs guides more appropriate support interventions; recent studies have found that carers of people at the end of life who were supported using CSNAT experienced significantly lower levels of grief, better psychological and physical health, were more likely to feel the place of death was right, and patients were more likely to die at home.<sup>5</sup>
- 4.2 In partnership with the University of Manchester, Hospice UK is researching practices at UK hospices with regards their support for carers. The first phase of this research outlined ten recommendations to hospices for providing comprehensive, person-centred assessment and support for family carers towards the end of life, including:
- 4.2.1 Consistent identification of carers
  - 4.2.2 Routine identification of carers' needs
  - 4.2.3 Training staff in carer assessment and support
  - 4.2.4 More time available for staff to support carers

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<sup>2</sup> Rowland, Christine; Hanratty, Barbara; Pilling, Mark; van den Berg, Bernard; Grande, Gunn. 'The contributions of family care-giving at end-of-life: a national post-bereavement census survey of cancer carers' hours of care and expenditures.' In: Palliative Medicine, Vol. 31, No. 4, 01.04.2017, p. 346-355.

<sup>3</sup> Marie Curie, (2015) 'The hidden costs of caring'.

<https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/december-2015/hidden-costs-of-caring.pdf>

<sup>4</sup> See the CSNAT website. Available at: <http://csnat.org/>

<sup>5</sup> Røen, Ingebrigt ; Stifoss-Hanssen, Hans ; Grande, Gunn; Brenne, Anne-Tove; Kaasa, Stein ; Sand, Kari ; Knudsen, Anne Kari 'Resilience for family carers of advanced cancer patients—how can health care providers contribute? A qualitative interview study with carers.' In: Palliative Medicine, 2018.

- 4.2.5 Setting up a system to record carer information separate from the patient so that the carer is seen as a beneficiary in their own right.<sup>6</sup>
- 4.3 The work of this project is on-going. The next phase is a national survey of carer assessment and support within UK hospices. The purpose of the survey is to understand the current provision for carers in organisations which focus on palliative and end of life care, highlight examples of best practice and identify gaps in service delivery. Results of the survey will be published towards the end of 2018.

## Hospice support for carers in Wales since the introduction of the Social Services and Wellbeing Act (2014)

### Assessments of need

- 5.1 Carers of adults with terminal and life-limiting conditions are likely to see a health body – either a charitable hospice or an NHS service, including primary care – as their first point of contact, rather than the local authority. With this in mind, there is a responsibility on palliative care providers to identify carers and proactively support them. Carers of children with palliative care needs are likely also to be in contact with further statutory agencies to support the child to meet their social care and education needs but children's hospices will be in an expert position to advise and support families with a dying child.
- 5.2 For charitable hospices, there is no statutory requirement to undertake an assessment of carers' needs, though many hospices will employ qualified social workers or family liaison teams who will have expertise in this area. Each hospice will take a different approach to assessing carers' needs, dependent on hospice resource and capacity and on the local connections with the local authority, health care and other third sector providers of support for carers.
- 5.3 While some hospices in Wales will make an informal and proportionate assessment of a carer's needs, signposting the person to relevant third sector organisations for support or referring on to the local authority for a formal carer's assessment, other hospices have formalised their approach to assessing carers' needs and are able to intervene to support carers and families prior to the engagement of statutory local authority support.
- 5.3.1 Nightingale House Hospice – a case study
- 5.3.2 Hospices across North Wales have had access to a train the trainer course on implementing CSNAT, which has been promoted and funded by Betsi Cadwaladr University Health Board (BCUHB) across its NHS and charitable end of life services. Following this initiative, Nightingale House Hospice in Wrexham has cascaded the training on this approach to carers' needs assessment through ensuring that all members of the clinical team have CSNAT training as part of their mandatory training. This means that their day therapy unit and their family support team (those teams that support patients residing in their own homes where there is likely to be a carer(s) involved) are systematically identifying and assessing the needs of carers of dying people.
- 5.3.3 This initiative is in its early days, with the approach gradually being rolled out since 2017. However, initial data suggest that, of the 55 carers who were assessed using the CSNAT initial questionnaire, 80 per cent went on to have a full interview with a trained professional to thoroughly assess their support needs. Of these, around two thirds (66 per cent) received action plans to support them in their care journey. Notably, 11 per cent of people identified as carers chose not to engage with the offer of an assessment and five per cent were unable to engage in the assessment process because the person they cared for was too ill or had deteriorated

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<sup>6</sup> See the full report and recommendations at: Ewing G and Grande GE. 'Providing comprehensive, person-centred assessment and support for family carers towards the end of life: 10 recommendations for achieving organisational change.' London: Hospice UK, 2018.

rapidly, demonstrating the particular challenges in accessing and supporting carers of dying people.

- 5.3.4 The support offered to those carers who were assessed as requiring action plans to enable them to maintain their caring roles ranged from referrals to coffee mornings at the hospice specifically set up for carers (including some specifically to support carers of people with designated conditions) or to 'Looking after me' wellbeing and resilience sessions; to referrals to third sector organisations offering befriending and sitting services; or, where it was deemed the person may be eligible for support, to the local authority for a carers' assessment under the Social Services and Wellbeing (Wales) Act.
- 5.4 Across the country, hospice employees leading on carers' needs – such as social workers and family liaison teams – report a greater awareness of statutory carers' assessments and, in some cases, report that local authority carers' teams are reaching out to hospices to improve access to carers of people with terminal or life-limiting conditions. However, there is no clear data to demonstrate whether this has translated into a greater number of carers of dying people being given a full statutory carers' assessment. Anecdotally, we hear that assessment remains informal and carers are likely to be signposted to third sector support networks as opposed to the local authority to determine their eligibility for a formal support plan under the Social Services and Wellbeing Act.

### **Provision of support, including respite**

- 5.5 Hospices offer a range of support for carers, depending on the hospice's resource, capacity and set up and the local availability of dedicated carer support services. With the make up of hospice service models varying greatly across Wales – for example, either primarily as an inpatient facility or primarily as a hospice at home service (with no bedded facility) – there is no standard service offer for carers from hospices across Wales and, consequently, the offer of service varies between areas.
- 5.6 Common carer support services include:
- 5.6.1 day hospice activities, which can be for carers only or for patients and carers to attend together
  - 5.6.2 befriending or sitting services, where a volunteer or trained professional (dependent on the patient's clinical needs) visits the patient in their own home, allowing the carer to have time to themselves
  - 5.6.3 wellbeing activities, such as complementary therapies
  - 5.6.4 pre-bereavement and bereavement support, which can range from informal group coffee mornings to specialist one-to-one counselling
  - 5.6.5 specific carer support initiatives, for example art therapy groups, cooking and nutrition support
  - 5.6.6 formal respite schemes (see below)
- 5.7 With regards to the provision of respite specifically, the hospice service model will have a greater impact on the service offered. For example, Shalom House in Pembrokeshire primarily serves as an inpatient respite facility, offering stays of up to five days for the people it cares for; Marie Curie in Penarth have offered a volunteer-led sitting service, which provides a block of three hours respite for carers each week; and the majority of hospices (whether bedded or not) offer day centre activities for patients, which double as respite for the carer.
- 5.8 While some aspects of the support for carers (such as an inpatient stay) will be partially funded through statutory sources, the vast majority of carer support provision will be funded through charitable giving and grants. All hospice services are free of charge to those using them.

### **Provision of information, advice and assistance**

- 5.9 Hospice staff play a crucial role in directing carers to local authority information, advice and assistance facilities as well as in the provision of informal information, including signposting to relevant agencies.
- 5.10 The majority of hospices state clearly that they offer support to families and carers as well as to the patient. However, while most people are aware that hospices provide medical care, far fewer are aware of the wider services on offer.<sup>7</sup> This limited perception of hospice services extends to other service providers as well as the public, which has implications for local authority information, advice and assistance services and may mean that fewer carers accessing this service are informed of how their local hospice could support them as well as the cared-for person.
- 5.11 There is a responsibility on hospices and local authority information, advice and assistance services to promote and raise awareness of the variety of services offered by local hospices – both to people with palliative care needs and their carers.

### **Information collected by local authorities and health boards on carers and their needs**

- 5.12 Of the seven published regional statutory population needs assessments under the Social Services and Wellbeing Act, only one (West Wales Region) refers in any detail to carers of people at the end of life and one other (Cardiff and the Vale Region) tangentially touches on this group of need with reference to the impact of bereavement on older people.<sup>8</sup>
- 5.13 Hospice UK strongly advocates that the needs of carers of people with terminal and life-limiting conditions are addressed in future statutory population needs assessments under the Social Services and Wellbeing Act. This should include an assessment of need, unmet need and provision of services such as:
- 5.13.1 Services for families with children with palliative care needs, including for siblings
  - 5.13.2 Bereavement support, including pre-bereavement and specialist counselling
  - 5.13.3 Respite, including inpatient facilities and sitting services.
- 5.14 Hospice care providers in Wales should play a part in supporting local authorities and health boards to collect the relevant data on people with terminal and life-limiting conditions, and their carers, that will inform future assessments of need.

### **For further information**

6. Please contact [REDACTED]  
[REDACTED], based at [REDACTED]

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[REDACTED] UK and ComRes 'Hospices survey: 7-8 August 2017' [http://www.comresglobal.com/wp-content/uploads/2017/10/Hospice-UK\\_Public-Perceptions\\_Data-Tables\\_part-1\\_October-2017.pdf](http://www.comresglobal.com/wp-content/uploads/2017/10/Hospice-UK_Public-Perceptions_Data-Tables_part-1_October-2017.pdf)

<sup>8</sup> See the published Statutory Population Needs Assessments by each region for further detail.