

The role of social workers in palliative, end of life and bereavement care

Association of Palliative Care Social Workers in collaboration with the former College of Social Work and Making Waves Lived Experience Network/OPEN FUTURES Research, with support from the British Association of Social Workers and Hospice UK



THE VOICES OF PEOPLE WITH LIVED EXPERIENCE

'I think the most important support is time, the giving of time, people finding time for you, and the freedom to ask questions. Having someone independent to go to just to talk through and to say 'I'm upset, I'm confused' and just to gain reassurance, because it's an awful thing to do, to have to take your loved one and leave them behind - a dreadful thing.' (Bereaved husband in his sixties)

'I visited my mother daily. I cleaned and shopped and I provided personal care. I showed her that I loved her and one day she asked why was I so good to her when she had been so unkind to me? I did not have an answer. My mother did not want to live past the death of her husband and I think that she gave up at that point. She just didn't care about living. In the end she just starved herself to death. I tried my best to keep her with me but she wanted out. It was terrible, terrible to see her go like that.'

'I was deeply depressed and then I became psychotic again. I feel I can't forgive her for making her dying one final act of neglect and indifference towards me, and this makes me unforgiving in turn to myself. It is coming up on three years since she died and 10 months since I was discharged after a four month stay in hospital. I want to let her go but it is difficult.' (Bereaved daughter in her fifties)

'I have a wedding in March, in Wales, and I hope I will be strong enough to go. Who knows if I'll be strong enough. The chemo has made me very sick and I've had lots of after effects. Who knows if I'll get to this wedding. I just take things as they go, day by day.'

'I want to protect my daughter, my family. But I'm able to talk with my sister. I want health workers to be positive and express what is going on in the right way without being negative. I am very positive about my life. I can talk to friends and it is helpful.' (Phone interview with woman who uses a drop in centre)

We have aimed to keep the voices of people with lived experience at the heart of this resource. Making Waves Lived Experience Network/OPEN FUTURES Research interviewed people who were willing to talk or write about their lived experiences of approaching death, caring and bereavement and what mattered most to them. The authors are grateful to all those people who were willing to share their stories.

Quotes and some longer extracts from these accounts have been interspersed within this resource. The complete versions are available on the Association of Palliative Care Social Workers website www.apcsw.org.uk

CONTENTS

Contents	3
Introduction	4
Structure of the resource	5
The context of palliative, end of life and bereavement care	6
Why do we need this resource?	8
What is palliative care social work?	9
Our vision for excellent social work in palliative, end of life and bereavement care	10
What can palliative care social workers do?	12
What can all social workers do?	17
What palliative care social workers offer	18
1. In palliative care and end of life settings	18
2. In the last few days and hours of life.....	21
3. To support wider social care and health	24
What all social workers offer	27
How can we get the most out of social work?	29
Conclusion	33
Final words: a narrative of survival	34
Appendices	35
Appendix 1: The role of social work in palliative, end of life and bereavement care	35
Appendix 2: Checklist for employers, leaders, commissioners and funders	39
Appendix 3: About the Association of Palliative Care Social Workers	40
Appendix 4: Learning needs analysis for social workers	41
Appendix 5: Links to other work	42
Appendix 6: Working group members.....	45
Acknowledgements	46

INTRODUCTION

*'I sit with her for over an hour while she explores her emotional and spiritual pain.'*¹ (Palliative Care social worker)

Social work has an important role in the delivery of meaningful palliative, end of life and bereavement care. Some social workers are palliative care social workers, working in services which specialise in this area of support. All social workers will encounter people who are experiencing loss, the end of life or bereavement.

This resource aims to ensure that people benefit from good social work at the end of their life, and that those close to them are supported during this time and into bereavement.

For specialist palliative care social work

The resource sets out what palliative care social work is, the role and expertise of palliative care social workers and what palliative care social work can offer to support people. It aims to:

- Help palliative care social workers to explain their role, to develop their expertise, and to be valued and valuable
- Help people who need palliative, end of life and bereavement care to understand how palliative care social work can help them
- Support other professionals, organisations, agencies and groups to benefit more from the input of palliative care social workers
- Support employers, leaders, commissioners and funders to get the most out of palliative care social work.

For social work in other areas

The resource sets out what all social workers can do and what they can offer to support people. It aims to:

- Help all social workers to be ready to support people who are dying or bereaved
- Help people, who need palliative, end of life and bereavement care to access support through social workers.

The resource was developed by the Association of Palliative Care Social Workers in collaboration with the former College of Social Work. Making Waves Lived Experience Network/OPEN FUTURES Research have been involved throughout to ensure that the resource is informed by the voices of people with lived experience.

(Please see Appendix 6 for members of the working group and acknowledgements).

¹ <http://www.theguardian.com/social-care-network/2013/sep/13/specialist-palliative-care-social-worker>

STRUCTURE OF THE RESOURCE

Good palliative, end of life and bereavement care relies on a range of formal and informal support. We trust that this resource will be accessible and clear to anyone who wants to know more about the role of social work. There are also appendices that provide additional information for social workers and those who support or work with them.

The resource starts with an overview of the context and an explanation of what palliative care social work is.

It then sets out the particular capabilities (skills, knowledge and values) that palliative care social workers have, and the general capabilities that all social workers have in relation to end of life and bereavement.

It explains what palliative care social work offers: in palliative care and end of life settings; in the last few days and hours of life; and to support wider social care. It then explains what all social workers can offer for people who are dying and bereaved and those who are close to them.

The resource finishes with actions that everyone can take to get more out of palliative care social work and social work at end of life and in bereavement.

We suggest that you use the *Contents* page to look at the sections that are most useful to you. We invite everyone to look at the sections on *Our vision for excellent social work in palliative, end of life and bereavement care*, and *How can we get the most out of social work?*



THE CONTEXT OF PALLIATIVE, END OF LIFE AND BEREAVEMENT CARE

***'When I think about the palliative journey with a loved person, one thing which I never saw anywhere in any guidance was just how physically and mentally shattering that experience is – be prepared to be physically and emotionally exhausted for months afterwards. I was ok at the time, working three days a week and seeing Cathy twice a day - I just kept going and going – it was all for Cathy – and when it was over it took me months and months to recover. People need to know how bloody tough this is going to be. We shouldn't protect people. This isn't going to be easy. It's going to be bloody tough.'** (Bereaved husband in his sixties)*

Palliative, end of life and bereavement care matters to everyone. Around half a million people die each year in the United Kingdom (UK).² Generally people are living longer but sometimes this means that people with a life-limiting illness are living with more complex needs than before. Some deaths are expected. Others are sudden or unpredictable. Many people, especially older people are not recognised as dying in time to prepare the support that they would prefer. Three-quarters of bereaved people say they did not get the support they needed.³ The UK is a diverse country and people's background, culture, beliefs and experiences affect their preferences, wishes and experiences around death, dying and bereavement.

In the UK, changes in the way society views death have impacted on the experience of people who are dying and bereaved. Generally people find it difficult to talk openly about dying. This makes it more difficult to get support and to ensure that people's wishes are fulfilled.⁴ All of us can be supported to consider what will matter to us when we are at the end of our lives, to plan ahead and to live well until the end of our lives.

Each country of the United Kingdom has a national strategy for end of life care. In recent years, many reports have been published to support good care. The strategies and main reports are summarised in Appendix 5. The most recent developments in palliative and end of life care in the UK contain some important themes:

- The principles of dignity, respect, involvement, choice and control at the heart of everything that happens
- The need to ensure comprehensive, timely, consistent, quality support for anyone who needs it, wherever they are
- Recognition that palliative and end of life care is for families, loved and close ones, as well as the dying person
- The importance of raising awareness and ensuring that communities can support end of life and bereavement experiences
- The importance of treating each person and situation individually, while using evidence of what is likely to work
- Support that starts early and goes through to bereavement
- Particular support in the last few days of life

² <http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/index.html>

³ <http://dyingmatters.org/news/brits-paying-price-refusal-discuss-death>

⁴ <http://www.dyingmatters.org/>

- The need for some specialist care, alongside general skills and knowledge for workers in all agencies and organisations
- The need for organisations, managers and commissioners to support workers
- The importance of different professions, organisations and agencies working well together, especially health and social care
- The need to share expertise more widely
- The need to better understand what works for people.

One of the most recent UK documents that highlight what is required is the *Ambitions for Palliative and End of Life Care: A national framework for local action 2015- 2020*.⁵ This summarises what good support looks like:



Good palliative, end of life and bereavement care addresses physical, psychological, social, cultural and spiritual needs. It is founded on values and requires skills and knowledge. Everyone providing support needs to be supported themselves. It is at its best when everyone works together.

⁵ National Palliative and End of Life Care Partnership (2015) *Ambitions for Palliative and End of Life Care: A national framework for local action 2015- 2020*, www.endoflifecareambitions.org.uk

WHY DO WE NEED THIS RESOURCE?

'I love my home and it's where I have chosen to be. I have a hospital bed downstairs and they've made everything just right for me to be at home.'

'Any decisions that need to be made are discussed between my wife and myself and then with the professionals. That's how we want it. And it will be my wife who makes decisions for me, when I'm no longer able. But I have it all written down, things of importance to me. It's all written down.' (Man in his eighties attending a hospice day centre).

Social work is essential to palliative, end of life and bereavement care. Some social workers deliver specialist palliative care social work; many others encounter people who are close to or at the end of their life, or are becoming or are bereaved. Social workers have a great deal to offer. However, they may not recognise how their role and expertise can make a difference.

The Social Care Framework⁶ identified the need to:

- Strengthen the specialism of palliative care social work
- Develop end of life capabilities (skills, knowledge and values) for all social workers.

Various initiatives have aimed to support this, in particular:

- The development of social care champions in palliative and end of life care including social workers
- A 2012 resource for social workers called *The route to success in end of life care – achieving quality for social work*⁷ which set out steps for better social work in end of life. This highlights the core role and unique skills that social workers have in 'maintaining a focus on the dying person in their family, community and cultural context' (page 36).

Social workers must work in partnership with people they offer support to. They work alongside other professions, agencies, organisations and as part of the wider community in which they are based. Social work expertise complements the knowledge of others such as nurses, occupational therapists, physiotherapists, counsellors, psychologists, advocates, chaplains and doctors; as well as the inherent wisdom of communities.

The resource reflects what we know is needed in palliative, end of life and bereavement care, and what other reports have asked for. It will help social workers to offer the best support that they can, and help others to work well with social work and get the most out of it.

⁶ End of Life Care Programme (2010) Supporting People to Live and Die Well: a framework for social care at the end of life

⁷ NHS Improving Quality and The College of Social Work (2010) The route to success in end of life care – achieving quality for social work

WHAT IS PALLIATIVE CARE SOCIAL WORK?

We use the expression ‘**palliative, end of life and bereavement care**’ to cover the range of support that people may need associated with dying and death. We include some definitions for these below and then specifically address what we mean by **palliative care social work**.

Palliative care – is an approach that improves the quality of life of patients who are facing the challenges associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.⁸ Palliative care includes supporting families and others who are close to the dying person and seeks to enhance remaining life opportunities.

End of life – people are ‘approaching the end of life’ when they are likely to die within the next 12 months.⁹

Bereavement – is the time we spend adjusting to loss. There is no standard time limit and there is no right or wrong way to feel during the bereavement period - everyone needs to find a way to live with their grief in their own way.¹⁰

Social work – helps adults and children to be safe and to have control in their lives.¹¹ Social work promotes social change and development, social justice, human rights, collective responsibility and respect for diversities. Social work engages with people, communities and structures to address life challenges and enhance wellbeing.¹²

Social workers – recognise when people in crisis are struggling, feel alone and need help to sort out their problems.¹³ They support individuals, groups and communities to recognise and develop their own strengths, to access the services they need and to get the resources they are entitled to.

Palliative care social workers – specialise in working with adults and children who are at the end of their life, their families, those they are close to and their communities. They use their particular skills and knowledge to help people to deal with the impact of what is happening to them, including loss and bereavement, and to have a good life and a good death. They work in partnership with people they offer support to. They work alongside other professions, agencies, organisations and as part of the wider community in which they are based. They bring social care expertise and perspective to situations in order to ensure that people get the support they need. Palliative care social workers may work in hospices or hospitals, in the community, or in prisons.

‘Enabling people to live their lives exactly as they want – it’s more than the medication, it is something aside from treatment. Comfort? Peace of mind?’
(Bereaved man in his sixties)

⁸ <http://www.who.int/cancer/palliative/definition/en/>

⁹ National Palliative and End of Life Care Partnership (2015) Ambitions for Palliative and End of Life Care: A national framework for local action 2015- 2020, www.endoflifecareambitions.org.uk

¹⁰ <http://www.counselling-directory.org.uk/bereavement.html>

¹¹ Social work Task Force (2010) Building a safe, confident future

¹² Adapted from International Federation of Social Workers (2014) Global definition of Social Work

¹³ Social work Task Force (2010) Building a safe, confident future

OUR VISION FOR EXCELLENT SOCIAL WORK IN PALLIATIVE, END OF LIFE AND BEREAVEMENT CARE

'We were fully involved in Cathy's end of life care but I think that's more of an indication of the inherent strength of the family, which my wife particularly had put together. Our children are all grown up and able to be very adult about all of this and at the point where Cathy felt she was going down - pretty well decided she was not going to have any more treatment, we actually sat in the hospice and had an end of life conference, with my two children who live in Nottingham, my eldest daughter in London who was on SKYPE, the district nurse service and hospice staff discussing what the options were.

And Cathy was really leading that conversation, and I think because she was able to lead the conversation at that stage, what it meant was that later on when she couldn't make decisions for herself, we already knew what her preferred options were, and once that was done and in place then the system was very supportive.

You didn't not listen to Cathy! Oh you didn't not!! She was very, very quiet but she was clear about things. She approached the whole thing with such clarity, and so level headed about it all. It was me who was emotional.'
(Bereaved husband in his sixties)

Our vision is that

People will have access to a palliative care social worker with the capabilities and resources to help them when they need it, and

All social workers will be able to help people, their families, and those close to them to realise the value of what they can do and give to each other at the end of their life and during bereavement, and to get the support they need.

For this to happen we think that the following things are needed:

- All social workers are able to learn from people who experience end of life and bereavement
- Everyone knows what palliative care social work is and what it offers, and how to access palliative care social work
- All social workers learn about loss, grief and bereavement
- Social workers see palliative care as a core part of all social work practice, as well as a specialist route they can take
- Palliative care social workers have the support they need to develop their expertise, to practice well, to share their expertise and to demonstrate their impact
- Palliative care social workers are available as a resource for other social workers
- Social workers are supported to see end of life and bereavement care as an important part of their role.

Ultimately, we aspire to all people and communities being aware of and able to access the social work support that they need. For this to happen, it is essential that social workers take the lead in developing their expertise and advocating for what they can offer. We hope that other professions, agencies and organisations will be enabled to work better with social workers, benefiting from the ways in which their different expertise complements each other. We also hope that employers, leaders, commissioners and funders will consider social work as part of their development of end of life, palliative and bereavement care.

'Over a period of six months we met on a regular basis and compiled his life story, letters to his wife and children, and lists of books and music that he loved. He handmade the envelopes for the letters and sealed them himself. We included books with handmade labels explaining why they were in the box and what they meant to him. When we were all happy that they were perfect I arranged to meet together with Jane and Tom gave her the boxes for safekeeping. This was a very emotional moment and Tom felt that he could not have done this alone. The couple expressed that they never cried together but this enabled them to do that. I supported them through this.

Tom's disease progressed as he knew it would and he was admitted to the inpatient unit. I was a familiar face from the day of admission and that was of some comfort to him and his family. I supported them all and in particular his older brother who had spina bifida and was devastated to be watching his younger brother dying. I introduced him to our bereavement co-ordinator as he had a history of rejecting support and I felt he would benefit. This also helped the whole family who had expressed that it was difficult for them to deal with Michael's grief when they were struggling themselves.

Tom died after a short stay in hospice care. I stayed late and was able to say my goodbyes knowing that the family were well supported by the team of nurses and carers.

Tom had an impact on the whole staff team and I organised a reflective space the following week for staff to share memories and thoughts of their work with him and his family. It was well attended and enabled us all to express our feelings.

Rest In Peace Tom.'
(Palliative Care Social Worker)



WHAT CAN PALLIATIVE CARE SOCIAL WORKERS DO?

***'I do not like it, when people who have not been ill say to you 'Oh you are so brave!' I hate that. I just want to be treated as me. I still want to go to the theatre, enjoy myself on a day trip. Just see me as I was and forget the cancer. It's not all that I am.'* (Woman in her sixties/seventies in a hospice day centre)**

This section sets out the particular expertise and experience which palliative care social workers have developed.

In 2014 the European Association for Palliative Care's Task Force published a list of the *Core competencies for palliative care social work in Europe*. This explains the main areas of expertise that palliative care social workers have, along with the values and attitudes, knowledge and skills that enable social workers to work well in these areas.¹⁴ The working group used this list, along with our own experience in the UK, to inform the capability statements below.

We have grouped these capabilities into the areas of the Professional Capabilities Framework that social work uses in England.¹⁵ We recognise that each UK country has its own framework, however the nine areas of practice in the Professional Capabilities Framework is a helpful way of setting things out. For each area we give a statement of what palliative care social workers do and an explanation. We consider that palliative care social workers are working as specialists and so work at the level of experienced social workers. Supervisors, educators or managers work at an advanced level, or in some cases at a leadership level.

Social work complements what other professions offer. Palliative care social workers work in partnership bringing a unique perspective and expertise.

Professionalism

Palliative care social workers demonstrate advanced knowledge, skills and practice based in, and informed by, a set of values and attitudes.

***'We work holistically, combining emotional and practical skills, to enable people to achieve what matters most to them. We are active in improving things, we are flexible and adaptive, and we are at our best as enablers when we are least conspicuous.'* (Resource working group)**

Values and Ethics

Palliative care social workers demonstrate the following values and attitudes in all they do:

- A thorough awareness of, and commitment to, the palliative care approach and the principle of living your life the way that you want to for as long as possible
- A commitment to people's self-determination, supporting and enabling them to make decisions in their approach to the end of life and bereavement
- A commitment to consider people within their cultural, social and family context, recognising that the definition of 'family' varies widely

¹⁴ The European Association for Palliative Care's Task Force on Social Work in Palliative Care (2014) *Core competencies for palliative care social work in Europe: an EAPC White Paper*, www.ejpc.eu.com

¹⁵ www.basw.co.uk/pcf

- An understanding of the need to adapt practice and interventions to individual needs and location
- Confidence and sensitivity in finding the right time to begin to talk about death and dying, being aware that doing this sooner rather than later helps people to be in control, plan ahead and achieve what is important to them
- A non-judgemental approach that respects people's different choices, and that celebrates and honours the experiences and cultures that have influenced them
- Self-awareness and an ability to consider and challenge their own assumptions and bias.

'Our starting point as social workers is to find out what really matters to the people we are there to help and what needs to happen in order for them to have a 'good death' not just in the sense of what happens in their last hours and minutes but how they can live as well as possible for whatever time they have left.' (Resource working group)

Diversity

Palliative care social workers recognise and respond to the impact of diversity, disadvantage and discrimination on people's situation - in relation to gender, culture, ethnicity, age, disability, sexuality, religion and social class. They acknowledge and respect that people and communities choose to live and die in different ways. They are able to:

- Recognise and work in partnership with people who are less well heard and less well served and those who underuse palliative care services, to challenge the particular barriers to health and social care that they face
- Value and respond to specific cultural and linguistic differences and expectations
- Identify gaps and failings in services, systems and society in order to negotiate for appropriate support for everyone.

'Palliative care social workers champion the rights of people who are discriminated against, socially disadvantaged, or devalued such as people with disabilities, offenders or people dependent on drugs or alcohol. This recognises and redresses the imbalance where people whose needs for end of life care are the same as anybody else's may not fit in comfortably with the way that services are organised.' (Resource working group)

Rights and Justice

Palliative care social workers support the idea that end of life and bereavement care is a human right. They advocate strongly on behalf of dying people, families and closest ones, unpaid carers, friends and communities to ensure that their needs are identified and met. They are able to:

- Support people to make decisions and remain in control of what happens to them
- Work creatively within health and social care systems and structures, and support communities to achieve effective support
- Assist people to realise their own abilities and mobilise their own resources
- Advocate for people whose rights are often missed or unmet such as children, older people and minority groups
- Use authority where this is necessary to protect people from harm or abuse and enable them to be in control
- Challenge others, with or on behalf of those they are working with, at individual and agency level, to improve outcomes.

'We are always working with people who are important to the person who is dying, including extended family and close people, unpaid carers and their communities. We promote people's rights to have their wishes heard and acknowledged. We offer practical help with, for example, housing, financial and legal issues and general practicalities of life. We might support families to make care arrangements, and to access entitlements and benefits.' (Resource working group)

Knowledge

Palliative care social workers demonstrate the following knowledge in their work:

- How to keep people's personal experience at the centre of all that happens
- Key concepts in palliative care, especially the principle of helping people to live as well as possible, within their personal frame of wellbeing, until they die
- How social work theory fits with palliative care theory
- Social models of illness and disability – how people's physical and mental wellbeing and ability to exercise choice and control are affected by the way that others interpret, value and respond to their experience
- Theories about the nature of attachments and how this affects the way people experience loss
- Theories of loss, grief and bereavement
- The impact of diversity on death, dying and bereavement
- How physical, psychological, social and spiritual care overlaps
- The different and changing needs of dying people, families, carers and communities who experience a range of illnesses, deaths and bereavements
- The importance of listening to and harnessing informal networks in providing support
- The legislation and policy that underpin the provision of palliative, end of life and bereavement services, and that underpin people's rights
- Local health and social care structures, processes, systems and supports
- Where social work fits into the roles within different professions, organisations and agencies
- Models of how change can be achieved, including systems theory
- The current ethical principles and debates within palliative, end of life and bereavement care.

***'We are interested in the psychological, emotional, social, cultural and spiritual dimensions of people's lives because we believe that all these areas shape the way they think and feel and what matters to them. This includes understanding that people experience pain and distress not only from physical causes but also from other aspects of their lives, such as financial pressures, discrimination and oppression, relationship problems, fears for the future or the loss of a sense of meaning and purpose in their lives. We equally recognise that the same dimensions shape the way people build life experience, resilience and peace of mind. We will work with people in relation to any of these dimensions; in order to support them to live as well as they can, whatever that may mean to them.'* (Resource working group)**

Critical Reflection

Palliative care social workers recognise the complexity, changeability and uncertainty in decision-making: for the dying person, those close to them and for professionals. They are reflective and self-aware. They are able to:

- Weigh competing interests
- Use the support of managers and supervisors to manage their own and others' difficult feelings and situations
- Develop a culture of reflective practice in the wider team
- Seek, and act on, feedback from dying people and their families, colleagues, mentors and managers.

Beyond this, palliative care social workers play a vital role in providing emotional and psychological containment for the pain and distress that colleagues inevitably face in the course of their work.

***'The expectation that we can be immersed in suffering and loss daily and not be touched by it is as unrealistic as expecting to be able to walk through water without getting wet... We burn out not because we don't care but because we don't grieve. We burn out because we allow our hearts to become so filled with loss that we have no room to care.'* (Francoise Mathieu, 2012)¹⁶**

***'We provide emotional and psychological containment for colleagues. This is done formally through clinical supervision and reflective sessions when there has been a particularly difficult experience or death. But also informally. The door to the social worker's office is always open, literally and metaphorically. Social workers are there to help all staff wring the loss out of their hearts.'* (Resource working group)**

Intervention and Skills

Palliative care social workers demonstrate the ability to:

- Engage with dying people and close ones, unpaid carers, and communities
- Work collaboratively with them
- Experience and communicate authenticity, warmth, empathy and concern
- Ask and enable difficult questions and 'hold' other people's thoughts and feelings
- Promote the palliative care social work perspective.

In particular palliative care social workers are able to:

- Recognise the impact of loss, grief, death and dying on the whole family and the people who play a part in supporting the dying person
- Contribute to building and maintaining therapeutic relationships
- Support people to deal with conflict, anger and frustration in a helpful manner, seeking to strengthen and sustain relationships
- Provide clear, truthful and understandable information about all aspects of someone's condition and service options
- Work in partnership with dying people and those who are important to them to comprehensively assess their needs
- Work with people to plan their care, drawing on their own resources and networks as well as looking to other sources of professional or community support
- Help dying people and the people who are close to them to identify apparent changes in mental and physical capacity, and respond supportively
- Support people in decision making or ensure decisions are made in their best interests, using appropriate legislation
- Work with dying people and the people who are close to them to identify and meet needs arising from loss and bereavement
- Promote and enable the ability of individual people and groups to adapt and respond to end of life and bereavement
- Help people to identify when they are at risk of or have suffered abuse or neglect and to support them in making choices about what action they would like to be taken.

***'Palliative care social workers form a working relationship with an individual person, family, network or community that focuses on supporting them to discover and develop their strengths. They enable people to access and make sense of the information they need to make choices and to plan for the future. They use their understanding of systems to help individuals, families and other groups to negotiate relationship problems and to get the support they need from agencies and services.'* (Resource working group)**

¹⁶ Mathieu, F. (2012) The Compassion Fatigue Workbook, Taylor and Frances, p7.

Contexts and Organisations

Palliative care social workers work with other professions, organisations and agencies. They contribute to joint work in a spirit of collaboration, with awareness of confidentiality, and with confidence in their professional standpoint. They are able to:

- Work collaboratively with professions, organisations and agencies at all levels and across all borders of health and social care systems
- Contribute to the development of plans to put good palliative care at the core of provision
- Facilitate communication between dying people, their families and those who are close to them, unpaid carers, friends and people providing health and social care services.

***'There needs to be an emphasis on working with other health, social care and voluntary sector colleagues. Social workers need to ally with other professions and understand how their roles fit together – for example by looking at the Route to Success¹⁷ documents for other professions in end of life care. Experience shows that when everyone focuses on the person's wishes and needs as the most important it makes a real difference to them and to their close ones. Social workers can join with others to embed such good practice and support the voice of the dying person.'* (Resource working group)**

Professional Leadership

Palliative care social workers take a lead to:

- Support people and communities to make their voices heard and to achieve what is important to them at end of life and in bereavement
- Influence all organisations responsible for providing palliative, end of life and bereavement care to adopt an approach of co-production with people who have lived experience
- Support all agencies and communities to respond to people's needs
- Participate in and lead key discussions around service delivery in end of life and bereavement care
- Take up senior practice and management roles, and encourage more organisations to appoint social workers at this level
- Negotiate changes in working practices to improve collaboration between services
- Enhance the evidence base for, and learning and development in, palliative, end of life and bereavement care
- Use evidence to identify unmet need and improve service provision
- Teach and mentor others
- Look after themselves and support other members of the team in dealing with dying, death and bereavement.

***'A social worker in Glasgow and colleagues elsewhere found that the needs of people with learning disabilities were often overlooked or poorly responded to in end of life care. They set up a national network with and for the benefit of people with learning disabilities. This network now develops resources, conducts research and provides peer support for people with an interest in this area of work.'* (Resource working group)**

¹⁷ NHS Improving Quality and The College of Occupational Therapists (2011) The route to success in end of life care – achieving quality for occupational therapy
NHS Improving Quality and Royal College of Nursing (2011) The route to success: the key contribution of nursing to end of life care

WHAT CAN ALL SOCIAL WORKERS DO?

'I don't want sympathy, just support. I don't like people feeling sorry for me. It's just some support, I suppose, practical support. I have a 'labradoodle'; he's a fairly big dog. It's that sort of practical support that's useful. When people offer practical help, like walking my dog.

In the time ahead, I would like to travel. I'm planning to go to Australia - I have relatives. I want to go back to Turkey. Last year I didn't have a holiday but we used to go every year to Turkey. And I want to go on a cruise.

I don't want to think about approaching the end of my life. I'm determined to stay positive. But if you ask me to sum up the story of my life so far, I can tell you in one word – Variety – it's all been very varied.' (Woman attending a drop in centre, age unknown).

This section sets out the capabilities that all social workers have that they can use to support people who are dying and bereaved. Again, we have put these statements against the areas of the Professional Capabilities Framework, whilst recognising that different UK nations have their own frameworks. The British Association of Social Workers has published a position statement for all social workers on supporting people who are dying that emphasises the key principles that they should work to, including ethics and human rights.¹⁸

Professionalism: Social workers are ready to apply their knowledge, skills and values to recognise and support people who are dying, facing loss or bereaved.

Values and Ethics: Social workers recognise the impact of people's values and beliefs, including their own, on death, dying and loss; and are committed to the principle of living well until you die, whatever that means for someone.

Diversity: Social workers value people as individuals, and ensure their wishes and needs are respected at end of life and when bereaved.

Rights and Justice: Social workers ensure that people who are dying or bereaved, especially from marginalised or disadvantaged groups, can empower themselves and be enabled to get the support they need.

Knowledge: Social workers are aware of the impact of loss from knowing that you are or someone close is dying, from physical and other changes, from grief and from bereavement. They know how to use law, evidence and systems to support and protect dying people and those close to them.

Critical Reflection: Social workers are able to judge when specialist support is needed for people they work with who are dying or bereaved, and when they themselves need additional support.

Intervention and Skills: Social workers are able to engage with people who are dying or bereaved and those close to them to ensure they have the practical, emotional, psychological and spiritual support they need. This includes working with individuals, groups and communities.

Contexts and Organisations: Social workers are able to access advice, information and input from palliative care social workers when this is needed in their organisation.

Professional Leadership: Social workers remind others of the need to recognise and respond effectively to people who are dying and bereaved, act as mentors, and share learning about how to do this well. This includes advocating for people's rights and supporting them to access the information and help they need.

¹⁸ BASW (2016) BASW Position Statement – Social Work Support to People who are Dying
http://cdn.basw.co.uk/upload/basw_120859-5.pdf
BASW (2011) Code of Ethics <https://www.basw.co.uk/codeofethics/>

WHAT PALLIATIVE CARE SOCIAL WORKERS OFFER

'My family matter to me, family followed by friends, community is less relevant to me. I love smoking as you can see!

My independence is highly important to me. My husband died and I am fighting to keep my independence. My family help. My daughter did her downstairs disabled bathroom, it is fantastic; it's called 'Nana's Bathroom!'

Family customs are important, birthdays, celebrations. I have two adopted grandchildren. It's very important for us all to get together for occasions.

It has been hard to ask for help, I didn't want to and I couldn't find the words. But now I am coming round. I know it is terminal and I know I need help now.' (Woman in her sixties/seventies in a hospice day centre)

This is what we are aiming for in palliative care:

"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my (unpaid) carer(s)."¹⁹

This section sets out some of the particular ways that palliative care social workers achieve this aim: in palliative care and end of life settings; in the last few days and hours of life; and to support wider social care.

1. In palliative care and end of life settings

This section uses six elements (and statements that go with these) that are identified in the *Ambitions* document, which highlights areas that are recognised as important across the UK.²⁰ Each of the 'I' statements below is taken from this document. This section also draws on the *Route to Success* document.²¹

1. Each person is seen as an individual

I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.

Palliative care social workers:

- Help people to express what is important to them and to use the tools and legal powers that are available, such as advanced care planning, including advance statements, advance decisions to refuse treatment, emergency health care plans and lasting powers of attorney so that their wishes are respected
- Help people choose where to die and identify how to make this happen if possible
- Help people choose what happens to their body after death
- Use legislation to ensure the rights of people who are deemed not to have capacity to make a decision

¹⁹ National voices and The National Council for Palliative Care and NHS England (2015) *Every Moment Counts: A narrative for person centred coordinated care for people near the end of life*. London: National voices <http://www.nationalvoices.org.uk/node/563>

²⁰ National Palliative and End of Life Care Partnership (2015) *Ambitions for Palliative and End of Life Care: A national framework for local action 2015- 2020*, www.endoflifecareambitions.org.uk

²¹ NHS Improving Quality and The College of Social Work (2010) *The route to success in end of life care – achieving quality for social work*

- Support families who have made or been involved in making decisions to withdraw treatment from someone who is deemed to lack capacity
- Help people talk openly about dying and bereavement
- Help people to prepare to lose someone
- Help people tell their story and leave memories behind them
- Provide bereavement support such as group work, counselling, art groups, storytelling and signposting to other forms of help
- Make sure that the voices of children and young people are heard so that their needs can be met when an important adult in their lives is ill or has died
- Support parents to arrange care for their children after their death, including helping them to make any necessary legal arrangements
- Support families to make decisions for themselves with and for children and young people who are dying.

2. *Each person gets fair access to care*

I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

Palliative care social workers:

- Ensure that people can access the general and specialist care and support that they need
- Make sure that people's cultural, linguistic and spiritual needs are considered and responded to as the person wishes
- Provide careful support and negotiation about sensitive personal situations
- Advocate for people or arrange advocates for them so they can ask for what they need
- Ensure that people get the benefits, housing and other resources/support they are entitled to
- Give advice and information to unpaid carers about how to keep caring if that is what they and the dying person want to do
- Help people to make complaints, give compliments or make suggestions about care.

3. *Maximising comfort and wellbeing*

My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

Palliative care social workers:

- Talk to people about how they feel, help them deal with their worries, and draw on and develop their coping strategies
- Make sure people know that help and support is available if they need it, and have an understanding of what the options might be
- Help people to figure out how to achieve their personal goals
- Ensure that support takes account of characteristics like age, gender, ethnicity, disability, sexuality
- Support people to address issues related to body image and self-esteem, and to sexuality and relationships
- Use relevant legislation to protect the rights and dignity of people who are deemed to lack capacity to make decisions for themselves and ensure that these decisions are made in their best interests
- Help people to arrange and manage practical support for daily tasks
- Help carers to arrange and manage practical support and breaks
- Help dying people and those that are important to them to prepare for death and bereavement
- Make enquiries and arrange safeguards with people if they are at risk of abuse and neglect
- Use relevant legislation to help people when their liberty has been restricted.

4. Care is coordinated

I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

Palliative care social workers:

- Keep the focus on the person and those that are important to them
- Coordinate the provision of care by managing any paperwork and, if necessary, dealing with any bureaucracy
- Explain how care will work for people and help them have as much choice and control as possible
- Facilitate discussions that resolve chaos and conflict, and negotiate solutions to disputes about how people will live
- Develop systems that help agencies and organisations to share information and work together
- Work with dying people and those who support them to provide feedback when things go wrong
- Consider and co-develop alternative ways of meeting the needs of people who choose not to take up existing services.

5. All staff are prepared to care

Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.

Palliative care social workers:

- Raise awareness and develop skills to ensure that people feel supported within their communities
- Supervise, coach and mentor health and social care workers and volunteers
- Monitor care provision and work together with care workers to improve care
- Lead support groups for workers and volunteers to talk about the emotional impact of their work and build resilience
- Train and educate others
- Set up and contribute to communities of practice to share what works
- Undertake research, and share research findings and practice based evidence so that everyone is able to continue to learn about what people need and what has been found to be helpful.

6. Each community is prepared to help

I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying and to support each other in emotional and practical ways.

Palliative care social workers:

- Talk to and educate community groups, voluntary organisations and schools about how dying and bereavement matters, and how to support people well
- Help organisations and agencies write end of life and bereavement care visions, strategies, policies and plans
- Coordinate the input of volunteers, and provide training and emotional support to them

- Develop relationships with local communities and communities of interest (people who are brought together because they have important interests, beliefs or values that they share) in order to learn from them and support them to build their capacity to support dying and bereaved people and those close to them
- Campaign for better resources, systems and treatment for people, through their own local networks, the Association of Palliative Care Social Workers, the British Association of Social Workers and in partnership with other organisations.

In Wales, the vision for palliative care is set out in *Together for Health: Delivering End of Life Care*.²² This says that the aim is for people in Wales to:

- Have a healthy, realistic approach to dying, planning appropriately for the event
- Have access to high quality care wherever they live and die whatever their underlying disease or disability, devoid of any prejudice in relation to their personal situation.

'We received a referral for Adam, who had been released on compassionate grounds from prison and had taken unwell whilst staying in the homeless unit. Adam was offered a bed in our inpatient unit. He had no family connections or visitors. The only person Adam wished to see was his brother who was currently in prison.'

'I arranged a safe and secure way for Adam to access money, and to get clothes and other personal items. We negotiated an escorted visit with the Prison Service for his brother to visit. Following Adam's death, I supported his brother to register his death and arrange the committal. I arranged a grant for him to pay for this.' (Palliative care social worker)

2. In the last few days and hours of life

'I spent the last six months of my father's life sitting and sleeping in a chair at the side of his bed during the times he was in hospital. There was no possibility I would leave him there alone. That wasn't ever a possibility.'

'What mattered most at the end was family being there – my dad listening to his family talk to him and telling him it was ok to go now. It was jovial and loving but still extremely sad. He was so at peace that he just looked as though he had dozed off. No angst. No fear.'

'My dad was from St Kitts and as a Caribbean family we are very close and loving. During those months in the ward, I came to know many patients and their families. I saw many things. A nurse said to me that I probably understood more about death and dying than most of the health care team because of the closeness I had with people nearing the end.'

'I encouraged the daughter of another man on the same ward to ask for the things she said made her dad her dad; a shave, combing his hair and freshening him up. The man in the bed no longer looked like him. There were no shavers, they said, on the ward. So the daughter left her dad's side to go to other wards to ask for a shaver. She returned skipping with glee at being able to make her dad look the way he would have wanted to be. He passed away a short while after.' (Bereaved daughter in her fifties)

²² NHS Wales (2013) *Together for Health: Delivering End of Life Care*

This section sets out what palliative care social workers do to support people in the last few days and hours of life. The five priorities identified for improving end of life care across the UK in *One Chance to Get it Right*²³ are quoted as points 1 to 5 below. The section also draws on the *Route to Success* document.²⁴

1. *The possibility that a person may die within the coming days and hours is recognised and communicated clearly. The dying person and those close to them are supported to express their wishes as much as they are able and choose to do so. Decisions about care are made in accordance with the person's needs and wishes, and these are reviewed and revised regularly.*

Palliative Care Social Workers:

- Liaise between people who are dying and the professionals who are monitoring their illness
- Support people to give and to listen to bad news, and support them to ask questions and to work out what this means for them and the people they are close to
- Make sure that people have the support they need to make the choices that they feel are right for them
- Make sure everyone knows what people's wishes are
- Ensure that best interests decisions are made for people who are deemed not to have capacity to make a decision themselves
- Uphold people's human rights using the law
- Enable people to change their minds if they wish to.

2. *Sensitive communication takes place between staff and the person who is dying and, with their agreement, those important to them.*

3. *The dying person, and those identified as important to them, are involved in decisions about treatment and care.*

Palliative Care Social Workers:

- Help people to know whom to talk to about questions or concerns, and how to seek urgent help or how to access alternatives
- Help people to give information in the most appropriate way
- Act as an advocate or arrange advocacy
- Arrange interpreters or other communication support
- Make sure people aren't left out or included inappropriately
- Facilitate discussions where there is difference of opinion
- Help people to talk about how they feel and to come to terms with this.

4. *The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.*

Palliative Care Social Workers:

- Help family and close others say how they want to be involved in care
- Help family and others close to the person to get the practical and emotional support they need

²³ Leadership Alliance for the Care of Dying People (2014) *One Chance to Get it Right* Improving people's experience of care in the last few days and hours of life

²⁴ NHS Improving Quality and The College of Social Work (2010) *The route to success in end of life care – achieving quality for social work*

- Ensure people's spiritual, religious and social needs are identified and met
 - Help people to talk about how they feel and to come to terms with this
 - Help people plan what will happen immediately after death.
5. *Care is tailored to the needs and wishes of each individual person and delivered with compassion through their own personal care plan.*

Palliative Care Social Workers:

- Support the dying person, and others that they choose, to play as active a part as possible in planning their care at every stage
- Make sure that assessments include physical, psychological, social, cultural and spiritual needs
- Coordinate the care plan
- Arrange services rapidly
- Ensure care meets cultural, spiritual and linguistic needs
- Assess how things change and make changes to the support provided
- Provide practical and emotional support to dying people and those who are important to them up to and after death
- Help people get advice to deal with legalities and arrangements after death
- Help family and others to gather memories, and people to leave memories behind
- Follow up with people who are bereaved in the way that works best for them.

In Scotland, the principles for good care at the very end of life are set out in *Caring for people in the last days and hours of life*.²⁵ They are:

- Informative, timely and sensitive communication is an essential component of each individual person's care
- Significant decisions about a person's care, including diagnosing dying, are made on the basis of multi-disciplinary discussion

'Martha was an older woman who was admitted to the hospice to review medication and get help with insomnia. At this point, she was walking, although unsteady on her feet. She was sometimes confused, especially when her husband was not around.

***Martha suddenly became much less well and needed constant nursing care. I got access to funding for a nursing home, however she was not well enough to move. Martha died after a few days. Things had changed rapidly and we needed to keep her and her husband at the centre of everything – we made sure that they were fully involved in what happened and able to understand the choices that they had, even though these were limited.'* (Palliative care social worker)**

²⁵ NHS Scotland (2014) *Caring for people in the last days and hours of life*

3. To support wider social care and health

This section sets out what palliative care social workers do to support wider social care and health. It uses the ten objectives that are identified in *Supporting people to live and die well: a framework for social care at the end of life* which highlights areas that are recognised as important across the UK.²⁶ It draws on the *Route to Success* document.²⁷

1. Identify and raise awareness of the role of social care in supporting people at the end of their life among the public, the social and health care workforce and its management.

Palliative Care Social Workers:

- Work in partnership with people who have lived experience of death and dying so that people can learn directly from this experience
- Raise awareness about better practice in palliative, end of life and bereavement care for other social care workers through discussions, briefings and publishing accounts of their work
- Keep up to date with social care law, policy and practice, providing social care expertise to other professionals
- Show how social care has a vital role in improving care for dying people and those who are close to them, through their own practice and by providing support, advice, mentoring or formal education to colleagues.

2. Facilitate commissioning and delivery of person-centred, integrated care

Palliative Care Social Workers:

- Advocate for individualised and person-centred care
- Work with organisations and agencies to support seamless, collaborative, quality, individualised support.

3. Embed end of life and bereavement care within commissioning and inspection frameworks and standards for practice²⁸

Palliative Care Social Workers:

- Advise commissioners, funders, leaders and employers about good palliative, end of life and bereavement care
- Advocate for people to be informed as early as possible of their right to make plans for their end of life care and to get the support they need to do this
- Contribute to the production and implementation of policies, operational guidance, outcome and audit measures.

²⁶ NHS IQ (2010) *Supporting People to Live and Die Well: a framework for social care at the end of life: Report of the Social Care Advisory Group of the National End of Life Care Programme*

²⁷ NHS Improving Quality and The College of Social Work (2010) *The route to success in end of life care – achieving quality for social work*

²⁸ National social work practice standards are:

Care Council for Wales (2015) *The Social Worker; Practice Guidance for Social Workers registered with the Care Council for Wales*

Health and Care Professions Council (2012) *Standards of Proficiency for Social Workers in England*

Northern Ireland Social Care Council (2015) *Standards of Conduct and Practice for Social Workers*

Scottish Social Services Council (2014) *SSSC Codes of Practice for Social Service Workers and Employers*

4. *Strengthen the specialism of palliative care social work.*

Palliative Care Social Workers:

- Provide evidence about the impact of palliative care social work
- Share good practice in palliative care social work
- Provide input to social work learning and development to ensure that palliative care is integrated as a key area of good practice
- Advocate for and contribute to the development of a specialist qualification in palliative care social work at an advanced level.

5. *Promote understanding and best practice in holistic assessment of individuals, their carers and families at the end of life.*

6. *Promote earlier end of life care planning that builds on a holistic understanding of wellbeing.*

Palliative Care Social Workers:

- Use evidence, expertise and experience to develop and embed good practice in palliative, end of life and bereavement care.

7. *Educate and train social care workers to deliver high quality end of life care.*

Palliative Care Social Workers:

- Design and deliver learning and development about palliative, end of life and bereavement care
- Act as role models and leaders for good practice.

8. *Create a supportive work environment that enables social care workers to maximise their contribution to quality end of life care.*

Palliative Care Social Workers:

- Are a source of advice, information and help for other social care workers.



9. *Promote supportive communities through engagement with a wide range of community services.*

Palliative Care Social Workers:

- Raise awareness of death and dying
- Share learning with and learn from communities
- Recognise the wisdom and resources of communities and work with them to influence services to be responsive to their particular needs and choices.

10. *Work jointly with research commissioners and funders to establish a robust evidence base for good practice in social care support at the end of life.*

Palliative Care Social Workers:

- Support and advise on research that is needed and help to gather and use evidence
- Facilitate and undertake research to help understand and develop good practice in social work.

In Northern Ireland, recommendations for good palliative and end of life care are set out in *Living Matters, Dying Matters*.²⁹ To develop quality care, the general recommendations are that:

- Open discussion about palliative and end of life care should be promoted and encouraged
- The core principles of palliative and end of life care should be a component in all pre-registration training programmes in health and social care and in staff induction programmes across all care settings
- Mechanisms to identify the education, development and support needs of staff, patients, families, carers and volunteers should be in place to allow person-centred programmes to be developed
- A range of inter-professional education and development programmes should be available to enhance the knowledge, skills and competence of all staff who come into contact with patients who have palliative and end of life care needs
- Arrangements should be in place which provide families and carers with appropriate, relevant and accessible information and training to enable them to carry out their caring responsibilities
- A collaborative and collegiate approach to research and development should be established and promoted to inform planning and delivery, drive up quality and improve outcomes in palliative and end of life care.

'I set up a programme across the county to help social care staff to know about advance care planning. The message that we all have a right to make decisions about our future under law has been one that has really resonated. This involved working with all areas of health care and adult social care to ensure that all staff are equipped to help people to make plans in advance if they want to. One particular area of success has been working with the local authority to integrate advance care planning into the 'contingency' planning section of the social care support plan. People are more likely to be informed about their right to make decisions about their future care, and workers are better equipped to support them to record their choices appropriately.'
(Palliative care social worker)

²⁹ Department of Health, Social Services and Public Safety (2010) *Living Matters, Dying Matters: A Palliative and End of Life Care Strategy for Adults in Northern Ireland*

WHAT ALL SOCIAL WORKERS OFFER

'I'm trying to write about my life, for those I leave behind me. I haven't finished my life story. I keep getting stuck. It is still not in good form. But my mother never told me about the previous generations even though I wanted to know. So I want to leave a story for others.

I don't want to be lonely as my end of life draws near.

I do want to receive caring care, the kind care that my husband didn't always get. My end of life planning is all in place.

The Story Of My Life? Somebody knows something about me. I existed.' (Woman in a hospice day centre).

This section sets out some of the particular ways that all social workers support end of life and bereavement care. It uses the six steps that are identified in the *Route to Success* document, which highlights areas that are recognised as important across the UK.³⁰

1. Discussions as the end of life approaches

Social workers:

- Build relationships that enable discussions to take place
- Sensitively initiate discussions about the future
- Ensure everyone is involved who needs to be
- Refer people to other professionals for more support when appropriate.

2. Assessment, care planning and review

Social workers:

- Focus on promoting wellbeing and achieving what matters to each person
- Look at all needs and strengths
- Consider preventative services and changing needs in the future
- Advocate for support from other services
- Ensure people get benefits they are entitled to
- Balance individuals' and unpaid carers' needs
- Advise on and implement the relevant legislation and policy to support decision making
- Sensitively apply social care law, policy and practice to safeguard people when needed.

3. Co-ordination of care

³⁰ NHS Improving Quality and The College of Social Work (2010) The route to success in end of life care – achieving quality for social work

4. Delivery of high quality care in different settings

Social workers:

- Ensure people are at the centre of their care and have information about who is doing what
- Build relationships with specialist palliative care providers
- Support communication and information sharing so that care is joined up
- Work with other professionals, agencies and organisations to maximise quality of life
- Act as a point of contact as things change
- Monitor how care is helping people to achieve the things that matter to them
- Share good practice to ensure that people's needs are appropriately met across different settings.

5. Care in the last days of life

Social workers:

- Keep the focus on quality of life
- Ensure people have the information they need
- Deal with practical issues
- Provide emotional, social, cultural and spiritual support
- Ensure people are not alone if they don't want to be.

'Beth was struggling to manage but did not want support from strangers. Sheila was happy to help her with this. Beth and Sheila identified that what was important to them was to spend time together, and as a family, and to maintain the garden to a good standard, as Beth was becoming frustrated that she could no longer look after the garden which she loved.'

***'I was able to set up direct payments. Beth and Sheila chose to use this money to employ a gardener, buy extra childcare, and also to fund some days out as a family. This benefited them much more than a traditional personal care package would have done.'* (Social worker)**

6. Care after death

Social workers:

- Ensure people have the information and support they need to complete the associated formal processes and procedures
- Help people to find ways to live with loss
- Provide support for people who are left at risk as a result of losing someone
- Refer people for specialist support if they need this
- Provide emotional support to colleagues as part of developing a supportive reflective culture
- Share learning with others.

HOW CAN WE GET THE MOST OUT OF SOCIAL WORK?

'If you're asking me to sum up the story of Cathy's life and death – she was somebody who had approached life as if it was full of hazards – yet when the hazard came, it somehow liberated her. I think on reflection that she probably did more in that last year than in any previous year of her life and it almost seems in some peculiar way that dying gave Cathy true freedom and capacity. She discovered within her, the strength to live right to the end.'

'Looking back over our life together, we married young and at the time, we thought perhaps we had married far too young, but we saw towards the end of her life that we hadn't married too young after all. We were married for 41 years. (Bereaved man in his sixties).'

Ensuring that everyone has a good life until they die and a good death must be everybody's business. Social workers have an important contribution to make and we ask that others support them to provide this.

At the start of this document we set out our vision that:

People will have access to a palliative care social worker with the capabilities and resources to help them when they need it, and

All social workers will be able to help people, their families, and those close to them to realise the value of what they can do and give to each other at the end of their life and during bereavement, and to get the support they need.

This section sets out actions that we think are needed to make this happen.

All social workers are able to learn from people who experience end of life and bereavement

- All social workers and social work educators identify opportunities to hear the voices of people with lived experiences.

Everyone knows what palliative care social work is and what it offers, and how to access palliative care social work

- Palliative care social workers use this document to explain their role (see Appendix 1 for a summary)
- People use this document to ask for good palliative care social work
- All social workers promote this resource, take it to the highest level within their organisation and advocate for the importance of social work in palliative, end of life and bereavement care
- Palliative care social workers share this document with other professions, agencies and organisations to strengthen multi-agency work
- Palliative care social workers contribute to the learning and development of other health and social care professionals
- Palliative care social workers work with organisations, agencies, groups and communities to improve information about death, dying and bereavement using traditional format and social media
- Palliative care social workers share this document with local leaders to increase public understanding and support for palliative care social work
- Employers, leaders, commissioners and funders use this document to ensure they are getting the most out of palliative care social work (see Appendix 2).

All social workers learn about loss, grief and bereavement; and social workers see palliative care as a core part of all social work practice, as well as a specialist route they can take

- Educators use this resource to check how palliative care capabilities are covered in social work education and continuing professional development
- Educators involve palliative care social workers and people with lived experience of loss in design and delivery
- Palliative care social workers use the European competencies framework to help them identify learning goals in their appraisal.³¹

Palliative care social workers have the support they need to develop their expertise, to practice well, to share their expertise and to demonstrate their impact

- Palliative care social workers join the Association of Palliative Care Social Workers and use its Champions Network (see Appendix 3)
- Employers use the Standards for Employers of Social Workers³² to consider how well supported palliative care social workers are.

Palliative care social workers are available as a resource for other social workers

- Palliative care social workers join the online network for end of life care facilitators and social care champions³³
- Palliative care social workers make contact with local social work teams to establish a route for people at end of life to access palliative care support
- Palliative care social workers and social workers shadow one another
- Palliative care social workers and social workers inform each other about learning opportunities they can benefit from
- Palliative care social workers review the impact of their work through research and evaluation.

Social workers are supported to see end of life and bereavement care as an important part of their role

- Social workers consider how far they meet the end of life capabilities and ask their organisation for learning and development that they need (see Appendix 4)
- Employers, leaders, commissioners and funders build social work leadership for end of life care into their organisational structures.

³¹ The European Association for Palliative Care's Task Force on Social Work in Palliative Care (2014) Core competencies for palliative care social work in Europe: an EAPC White Paper, www.ejpc.eu.com

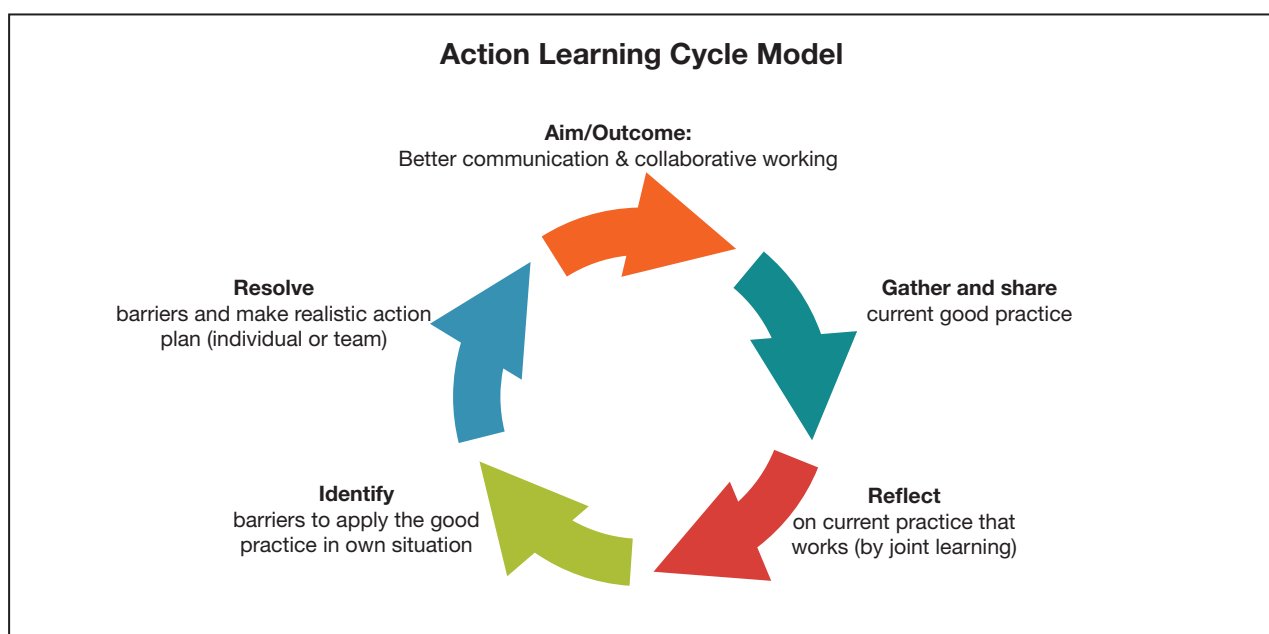
³² http://www.local.gov.uk/workforce/-/journal_content/56/10180/3511605/ARTICLE

³³ <http://www2.hull.ac.uk/fass/eolc.aspx>

Example: Champions project³⁴

The Association of Palliative Care Social Workers held workshops with palliative care social workers and social workers to identify how to ensure that local areas had a social care champion for end of life care. The key messages were that people who take on the ambition of improving end of life care need to:

1. Engage with managers at a sufficiently high level, within both specialist and local authority services, to promote this work against other priorities of the organisation
2. Recognise networking as essential: this takes effort but is well worth the time invested
3. Engage with cultural differences: these are to be expected across different organisations and if explored positively, can be tackled rather than being denied or becoming a focus for conflict
4. Encourage commissioning of joint funded posts
5. Be persistent: a strong theme emerged of the need for persistence in commitment to the value of collaboration
6. Use action learning: a model is presented below to illustrate the approach that was taken in developing and facilitating this collaborative workshop, and we suggest it provides a useful guide for continuing to tackle the topic in our practice.



³⁴ Hearn F and Adshead L (2014) Social Care Champions Workshops Project 2014, Association of Palliative Care Social Workers

Example: Co-produced change

The following is an account from someone with lived experience of how determined advocacy and the force of one dying man's personality achieved organisational change:

*'Sean Lynch's last months of living describe celebration, frustration, trust, hope, anger, and joy, feelings of connectedness or separation, tales of belonging but also of not belonging. Sean's death in February 2011 marks an eight month final journey led by Sean.'*³⁵

Sean describes himself as a 'working-man-tramp' and a big drinking man. He vehemently insists he will 'never change' – moreover does not want to change. This throws out big challenges to those who would curb his challenging life style and tidy up his dying.

In fulfilling many of his end of life wishes, wise or 'less wise,' and defining a very personal notion of wellbeing and the informal support that enables it, Sean resists more medical palliative care models to reach a peaceful and dignified death 'at home' in a Nottingham 'wet' hostel for older drinking men, surrounded by workers, friends and family.

[The] strength [of Sean's story] is Sean himself at its centre, guiding, challenging and inspiring everyone around him. Respect of partners is characterised by the willingness with which people are prepared to lay aside their own strong values and be led by Sean's wishes, regardless of how wise or 'appropriate' they might be deemed.

The alliance brings out the best in everyone and in particular highlights:

- the crucial role of other older residents as peer supporters and enablers*
- the flexibility and openness to change of committed care staff*
- and finally the purity and independence of independent advocacy which digs its heels in, to insist that Sean's personal blue print for living and dying remain at the centre at all times.*

As he starts to weaken the hostel makes a decision to move Sean to a local hospice. He does not know where he is going or why. The other older residents are not told where he is going or why. No one mentions his disappearance from the hostel.

The hospice is clean, caring and kind. The hospice is the last place Sean wants to be. Anxious and fearful, but unable to make himself understood, it is now up to myself as Sean's community advocate to fight his corner and insist that his final wishes are honoured. Some staff in the hostel resist. 'We don't do palliative' they protest. 'Well you do from now on' I reply. And the wonderful manager agrees.

Support from the hostel manager puts into place the extra provisions, the extra nurses, carers and the funding that will enable Sean's return. It is now the other residents, all older drinking men who become the big force within the partnership – sharing the final days with Sean in much the way they did before he became so poorly – beer cans and fags on the go.

Sean dies in the arms of the daughter whom he had lost touch with for most of her childhood and later life. He dies in the hostel he calls home. He dies surrounded by the men he has lived, work and drunk with all his life.

*The hostel has since experienced a massive cultural shift from a place of silence to a place where death is openly discussed and planned for by everyone and where opportunities to live up to the last abound. (Sean's advocate and champion from Making Waves)*³⁶

³⁵ This account is extracted from a book that was co-authored by Julie Gosling, a member of the Working Group for this resource (Gosling, J. and Martin, J. (2012) Making Partnerships with Service Users and Advocacy Groups Work, Jessica Kingsley)

³⁶ Reflections collaboratively written by Julie Gosling, Dave Milburn, Ian Nesbitt and Sean Travers Lynch (RIP) with contributions from Tom Coffey, Tom Sweeney, Pat Kelly, Joe McGrory, Mick Regan and residents and care staff at 32 Bentinck Rd

CONCLUSION

Our invitation

Ensuring that everyone has a good life until they die and a good death and that those close to them receive the support they need must be everybody's business. Social workers have an important contribution to make to this. We ask social workers to use this resource to review and to continue to develop their practice. We also ask that they promote this resource, take it to the highest level within their organisation and advocate for the importance of social work in palliative, end of life and bereavement care. We ask employers, leaders, commissioners, funders, colleagues from other professions and educators to recognise the contribution that social workers make in palliative, end of life and bereavement care and to provide them with the support they need to deliver this.

Learning from the voices of people with lived experience of death and dying

'We were a large Catholic family in Northern Ireland in the 60s and life was hard. Care was a thankless task. Of the eight of us I was the one and the only one to look after my mother and to care for the younger children. I was never thanked. My mother had breakfast in bed until the day she died but she never once gave love or gratitude towards me. It was all just taken for granted and that became the story of my life. I cared for a sister with cancer who demeaned me in every possible way. And the man who gave me children continued the bullying and the contempt.'

Trauma has left many marks. In my fifties I see and own the deepest depression since childhood and I am determined that my life will be different. I have forgiven my mother and the rest of them and I have let go of the bitterness that has weighed me down throughout my life. Counselling is helping. I am learning that I am capable, lovable, worth more. In peace, in faith, I feel no regrets for the care I gave to my mother up to and during her dying. It was my calling and I answered with all my heart.' (Bereaved daughter in her fifties)

The accounts of lived experience included in this resource highlight how important it is that people who are dying and those close to them are at the centre of all that happens. Their stories make it clear that support needs to take many different forms, and must be driven and shaped by the unique character, experiences and strengths of the people involved and those of the families, groups and communities in which they live.

One of the outcomes of this work is that the Association of Palliative Care Social Workers is establishing an open access collection of accounts of lived experience on our website. This will include the full versions of the interviews that are quoted in this resource. Making Waves/OPEN FUTURES Research will be adding further accounts in future and we invite others to do so as well. We hope that this will provide an increasingly valuable source of learning for social workers and many others.



FINAL WORDS: A NARRATIVE OF SURVIVAL

One of the most important messages from this resource is the importance of social workers having and taking opportunities to learn from people who have lived experience of death, dying and bereavement. So it seems fitting that the final words should come from an account in which a woman describes her own unique journey as a survivor of many life challenges, including caring for both her grandmother and her mother through their very different experiences of terminal illness and dying.

'I come from a line of strong women and hard lives. My great grandmother survived emigration from Ireland and the death of a husband who didn't. My own mother was abandoned by our father. We went to live with Mama [grandmother].

As a child I witnessed the violence of women on women and I was subject to it too. I learned that sadness is borne in silence and that rage suppressed, spills out mindlessly, harmfully. And in spite of all this, I learned as child that I was deeply loved.

Mama died at home in the care of my mother and I. She was happy to go. I was the person who told her she was dying and she was peaceful that her life was ending. I used to carry her on my back and we had lots of laughs about it. Her suffering was brief and in the final hours she saw people that we could not see and she spoke with them.

Mother love, a strong anchor, held me through my own abusive marriage, chaos, self-harm, self-medicating self-hate and more. My mother was my hero, self-made, flamboyant, successful - I followed in her wake to achieve academically, professionally and in a less positive way I inherited her emotional blue print. And for my mother and I both, where feelings were held down, the bodies screamed out in protest. I became asthmatic, arthritic and heart-sore (literally) while my mother grew the secret cancer that killed her.

Talking brought us closer together during the last two years.

Illness came quickly and lasted three months.

My mother died in hospital. In a ward full of older people, she was examined perfunctorily by a registrar, who, despite her protests forced a feeding tube into her. The terrified animal in her eyes lives within me still. We were then left alone and no-one came near us. 'We're too busy and we're short staffed' was the response to my calls for aid.

My mother wheeled unconscious into ICU and the consultant telling me it was only a matter of time.

I sat at my mother's side and I talked, I talked and I sang and I did not leave her in the darkness without the sound of my voice for one moment. Uncle Ken and our lovely Father Sean there too. In a brief silence as we gathered our feelings, my mother's eyelids straining to open as she looked for our voices. I told her that I had always loved her and she was the most beautiful person in the world and that Mama was waiting in Heaven. I sat holding her hand for seven hours, even though the nurses tried and failed physically to move me.

Ten years on and I think increasingly of my mother's life and death, far more than in the early days. In order to finish the deep talks we had begun I have needed to hold both my mother's imperfections and my own and not feel treachery where I have decided to tell and hear a story less than kind. I owe the story to us both.' (Bereaved daughter in her sixties).

THE ROLE OF SOCIAL WORK IN PALLIATIVE, END OF LIFE AND BEREAVEMENT CARE



'It's amazing how much better it felt when they stop trying to treat you – and the cancer – and support you in making the preparations and choices for the time you have left. We plan so much for birth and yet we are not tuned into planning for death, which is always inevitable.' (Bereaved daughter in her fifties)

Introduction

Palliative, end of life and bereavement care matters to everyone. Good palliative, end of life and bereavement care addresses physical, psychological, social, cultural and spiritual needs. It is founded on values and requires skills and knowledge. Everyone providing support needs to be supported themselves. It is at its best when everyone works together.

Social work is essential to palliative, end of life and bereavement care. Some social workers deliver specialist palliative care social work; many others encounter people who are close to or at the end of their life, or are becoming or are bereaved. Social workers have a great deal to offer. They must do this in partnership with people they offer support to, alongside other professions, agencies, organisations and as part of the wider community in which they are based. Social work expertise complements that of others such as nurses, occupational therapists, physiotherapists, counsellors, psychologists, advocates, chaplains and doctors; as well as the inherent wisdom of communities.

What is palliative care social work?

Palliative care social workers specialise in working with adults and children who are at the end of their life, their families, those they are close to and their communities. They use their particular skills and knowledge to help people to deal with the impact of what is happening to them, including loss and bereavement, and to have a good life and a good death. They work in partnership with people they offer support to. They work alongside other professions, agencies, organisations and as part of the wider community. They bring social care expertise and perspective to situations in order to ensure that people get the support they need. Palliative care social workers may work in hospices or hospitals, in the community, or in prisons.

What can palliative care social workers offer?

Palliative care social workers are committed to the principle of living your life the way that you want to for as long as possible. They recognise and respond to the impact of diversity, disadvantage and discrimination on peoples' situation. They advocate strongly on behalf of dying people and those close to them, families, unpaid carers, friends and communities to ensure that their needs are identified and met.

Palliative care social workers have particular knowledge and skills that help them to support people. They contribute to joint work in a spirit of collaboration, with awareness of confidentiality, and with confidence in their professional standpoint. They help others to develop their skills and knowledge, and they support colleagues.



1. In palliative care and end of life settings

Palliative care social workers:

- Help people to express what's important to them
- Help people talk openly about dying and bereavement and make choices
- Provide bereavement support such as group work, counselling, art groups, storytelling and signposting to other forms of help
- Support families to make decisions with and for young people and children
- Advocate for people or arrange advocates for them
- Ensure that people get the benefits, housing and other resources/support they are entitled to
- Make enquiries and arrange safeguards with people if they are at risk of abuse and neglect
- Use relevant legislation to ensure the rights of people who are deemed to lack capacity to make a decision
- Use relevant legislation to help people when their liberty has been restricted
- Coordinate the provision of care by managing any paperwork and, if necessary, dealing with any bureaucracy
- Facilitate discussions that resolve chaos and conflict, and negotiate solutions to disputes about how people will live
- Supervise, coach and mentor workers and volunteers
- Lead support groups for workers to talk about the emotional impact of their work
- Train and educate others, and carry out research.

2. In the last few days and hours of life

Palliative Care Social Workers:

- Liaise between people who are dying and professionals who are responding to their illness
- Help people to make the choices that they feel are right for them
- Uphold people's human rights using the law
- Facilitate discussions where there is difference of opinion
- Help people to talk about how they feel and to come to terms with this
- Help family and others say how they want to be involved and to get the support they need
- Ensure people's spiritual, religious, cultural and social needs are identified and met
- Support the dying person, and others that they choose, to play as active a part as possible in planning their care at every stage
- Coordinate the care plan and arrange services rapidly
- Help people get advice to deal with legalities and arrangements after death
- Help people to gather memories and leave memories behind
- Follow up with people who are bereaved in the way that works best for them.



3. To support wider social care and health

Palliative Care Social Workers:

- Work in partnership with people who have lived experience of death, dying and bereavement so that people can learn directly from this experience
- Advise commissioners, funders, leaders and employers about good palliative, end of life and bereavement care
- Provide evidence about the impact of palliative care social work
- Share good practice in palliative care social work
- Raise awareness, mentor, teach and support others
- Provide a source of advice, information and help for other social care workers.

How can we get the most out of palliative care social work?

Our vision is that people will have access to a palliative care social worker with the capabilities and resources to help them when they need it; and all social workers will be able to help people, their families, and those close to them to realise the value of what they can do and give to each other at the end of their life and during bereavement, and to get the support they need.

We think that the following actions will support this:

All social workers are able to learn from people who experience end of life and bereavement

- All social workers identify opportunities to hear the voices of people with lived experiences.

Everyone knows what palliative care social work is and what it offers, and how to access palliative care social work

- Palliative care social workers use this summary to explain their role, let people know what they offer and to advocate for palliative care social work
- People use this summary to ask for good palliative care social work
- This summary is shared with the public; with other professions, agencies and organisations; and with employers, leaders, commissioners and funders
- Employers, leaders, commissioners and funders use this summary to ensure they are getting the most out of palliative care social work.

All social workers learn about loss, grief and bereavement; and social workers see palliative care as a core part of all social work practice, as well as a specialist route they can take

- Educators check how palliative care capabilities are covered in social work education and continuing professional development
- Educators involve palliative care social workers and people with lived experience of loss in design and delivery
- Palliative care social workers use the European competencies framework to help them identify learning goals in their appraisal.³⁷

Palliative care social workers have the support they need to develop their expertise, to practice well, to share their expertise and to demonstrate their impact

- Palliative care social workers join the Association of Palliative Care Social Workers and use its Champions Network
- Employers use the Standards for Employers of Social Workers³⁸ to consider how well supported palliative care social workers are.

Palliative care social workers are available as a resource for other social workers

- Palliative care social workers join the online network for end of life care facilitators and social care champions³⁹
- Palliative care social workers make contact with local social work teams to support and to learn from one another
- Palliative care social workers review the impact of their work.

Social workers are supported to see end of life and bereavement care as an important part of their role

- Social Workers consider how far they meet end of life capabilities and ask their organisation for learning and development that they need
- Employers, leaders, commissioners and funders build social work leadership for end of life care into their organisational structures.

'I think the most important support is time, the giving of time, people finding time for you, and the freedom to ask questions. Having someone independent to go to just to talk through and to say 'I'm upset, I'm confused' and just to gain reassurance, because it's an awful thing to do, to have to take your loved one and leave them behind - a dreadful thing.' (Bereaved husband in his sixties)

To find out more read the full resource: The role of social workers in palliative, end of life and bereavement care (2016), accessible at: www.apcsw.org.uk/resources/social-work-role-eol.pdf or www.basw.co.uk/the_role_of_social_workers_in_palliative_care

Or contact the Association of Palliative Care Social Workers www.apcsw.org.uk

³⁷ The European Association for Palliative Care's Task Force on Social Work in Palliative Care (2014) Core competencies for palliative care social work in Europe: an EAPC White Paper, www.ejpc.eu.com

³⁸ http://www.local.gov.uk/workforce/-/journal_content/56/10180/3511605/ARTICLE

³⁹ <http://www2.hull.ac.uk/fass/eolc.aspx>

CHECKLIST FOR EMPLOYERS, LEADERS, COMMISSIONERS AND FUNDERS

What palliative care social work can offer	How well do we use this in our organisation? (1 low-5 high)	Comment	Action	By when	Complete?
Help people talk openly about dying and bereavement and make choices in advance					
Provide bereavement support through individual, family and group work					
Support families to make decisions with and for young people and children					
Advocate for people or arrange advocates for them					
Ensure that people get the benefits, housing and other resources/support they are entitled to					
Make enquiries and arrange safeguards with people if they are at risk of abuse and neglect					
Use relevant legislation to ensure the rights of people who are deemed not to have capacity to make a decision					
Use relevant legislation to help people when their liberty has been restricted					
Coordinate the provision of care by managing any paperwork and, if necessary, dealing with any bureaucracy					
Facilitate discussions that resolve chaos and conflict, and negotiate solutions to disputes					
Supervise, coach and mentor workers and volunteers					
Lead support groups for workers to talk about the emotional impact of their work					
Train and educate others					
Undertake research and provide information about findings so these are readily available					
Work with communities to learn from them about their strengths and needs; and work in partnership to enhance resilience in relation to death, dying and bereavement					

ABOUT THE ASSOCIATION OF PALLIATIVE CARE SOCIAL WORKERS

The Association of Palliative Care Social Workers is a membership organisation for palliative care social workers across the UK. We aim: to raise the profile of palliative care social work; to support and advise all palliative care social workers wherever they work; to inspire excellence by sharing best practice; and to promote high quality research and evaluation in order to continually improve end-of-life and bereavement care.

Our members are specialist social workers who are employed as practitioners, managers, researchers and educators in hospices, hospitals, local authority social work services and universities. We are about to introduce a new category of associate membership that will be open to social workers who are employed in other roles and others who have a particular interest in palliative, end of life and bereavement care. Former members who are no longer registered can remain associated with us as Friends of the Association.

We have a regional structure within which Regional Representatives convene regional meetings that combine an educational element with opportunities for mutual support and sharing of information. We hold an annual conference and other occasional national events throughout the year. We contribute to the work of national and international bodies and working groups relating to palliative, end of life and bereavement care, including the European Association for Palliative Care, and have formal and informal links to social work organisations such as the British Association of Social Workers.

The Association was established in 1987 under the leadership of its first Chair, Elizabeth Earnshaw-Smith. One of the Association's early and important achievements was to successfully lobby parliament to change the law, by establishing the 'special rules' for terminally ill patients applying for Disability Living Allowance (now Personal Independence Payments) and Attendance Allowance, which continues to benefit people today.

At the 2014 National Conference one of the founding members, Julia Franklin, expressed her surprise that an organisation that began with just a few social workers meeting over cucumber sandwiches at a London hotel had managed to effect change at a national and international level. She explained that she and her then colleagues had been simply 'opportunists...doing what we could from where we were.' We continue to do our best to follow her exhortation to take up the baton: to do what we can to improve the experience of dying and bereaved people, their families and communities, through our own practice and through influencing the work of others.

For more information about the Association please see our website

www.apcsw.org.uk



LEARNING NEEDS ANALYSIS FOR SOCIAL WORKERS

Capability	How well I do this (1 low-5 high)	Comment	Action	By when	Complete?
Social workers are ready to apply their knowledge, skills and values to recognise and support people who are dying, facing loss or bereaved.					
Social workers recognise the impact of people's values and beliefs, including their own, on death, dying and loss; and are committed to the principle of living well until you die, whatever that means for someone.					
Social workers value people as individuals, and ensure their wishes and needs are respected at end of life and when bereaved.					
Social workers ensure that people who are dying or bereaved, especially from marginalised or disadvantaged groups, can empower themselves and be enabled to get the support they need.					
Social workers are aware of the impact of loss from knowing that you are or someone close is dying, from physical and other changes, from grief and from bereavement. They know how to use law, evidence and systems to support and protect dying people and those close to them.					
Social workers are able to judge when specialist support is needed for people they work with who are dying or bereaved, and when they themselves need additional support.					
Social workers are able to engage with people who are dying or bereaved and those close to them to ensure they have the practical, emotional, psychological and spiritual support they need. This includes working with individuals, groups and communities.					
Social workers are able to access advice, information and input from palliative care social workers when this is needed in their organisation.					
Social workers remind others of the need to recognise and respond effectively to people who are dying and bereaved, act as mentors, and share learning about how to do this well. This includes advocating for people's rights and supporting them to access the information and help they need.					

LINKS TO OTHER WORK

Initiative	What this covers	How does this relate to social work?	How this resource responds
Strategic Framework for Action on Palliative and End of Life Care 2016-2021 (2015) The Scottish Government	The framework for setting out commitments to end of life and palliative care in Scotland	Makes a commitment to addressing the educational needs of the health and social care workforce	Used this to consider themes that matter and checked social work's offer against these
End of Life Care Strategy: promoting high quality care for all adults at the end of life (2008) Department of Health	The aims for end of life care in England	Mentions social work as one group which will need competencies	Used this to consider themes that matter and checked social work's offer against these
Living and Dying Well: A national Action Plan for palliative care end of life care in Scotland (2011) The Scottish Government	The aims for end of life care in Scotland	Social work is mentioned as part of examples of good practice	Used this to consider themes that matter and checked social work's offer against these
Living Matters, Dying Matters: A Palliative and End of Life Care Strategy for Adults in Northern Ireland (2010) dhSSPSNI	The aims for end of life care in Northern Ireland	Does not specifically mention social work	Used this to consider themes that matter and checked social work's offer against these
Together for health delivering End of Life Care (2013) NHS Wales	The aims for end of life care in Wales	Has goal to improve communication skills of health professionals and social care teams to talk to patients regarding end of life plan	Used this to consider themes that matter and checked social work's offer against these
One chance to get it right: improving people's experience of care in the last few days and hours of life (2014) Leadership Alliance for the Care of Dying People	Sets out a new approach to caring for people in the last few days and hours of life	Recognises role of social worker in communication and support for decision making	Used this document's priorities as the framework for what palliative care social work can offer in the last few days of life
End of Life Care, Fifth Report of Session 2014-15 (2015) Health Select Committee	Highlights the main areas for palliative care improvement including awareness of priorities of care, training, free social care, bereavement support	Has an action to develop a way of sustaining local communities of practice through the network of end of life care facilitators and social care champions supported by NHS Improving Quality	Used this to consider themes that matter and checked social work's offer against these
NHS England action plan for End of life care 2014-16 (2014) NHS England	Uses a House of Care model as a framework for setting out commitments to end of life care	Doesn't specifically mention social work	Used this to consider themes that matter and checked social work's offer against these
Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020 (2015) National Palliative and End of Life Care Partnership	Builds on the Department of Health's 2008 Strategy for End of Life Care; sets out six 'ambitions' – principles for how care should be delivered at local level	APCSW was involved in this Emphasises need for access to social care	Used the ambitions as the framework for what palliative care social work can offer in palliative care and end of life settings

Initiative	What this covers	How does this relate to social work?	How this resource responds
Supporting People to Live and Die Well: a framework for social care at the end of life (2010) NHS IQ	Key message that Social care has a vital role to play in supporting people to live and die well, in the place of their choosing Sets out 10 objectives aimed at improving social care at end of life	Talks about need to develop social work capabilities in end of life and make more of palliative care social work Identifies need to clarify role of social work in end of life care and articulate contribution of palliative care social work	Used the objectives as framework for what palliative care social work can offer to support wider social care and health
Online network for the end of life care facilitators and social care champions network, hosted by the University of Hull, Centre for End of Life Care Studies	Functions to link people across the network, enable discussion forums and promote a proactive approach to sharing and learning	Is a useful resource for social workers	Suggests palliative care social workers join the network as one of the actions
BASW Position Statement – Social Work Support to People who are Dying (2016) BASW	Clarifies the key principles underlying good practice in social work with people who are dying and their families; and the context needed to underpin this practice	Explains the position of BASW as the voice of social work in the UK and reflects the social work code of ethics	Used this to emphasise the importance of professional standards, ethics and human rights
The route to success in end of life care – achieving quality for social work (2013) The College of Social Work, together with the National End of Life Care Programme	Covers core values and skills, end of life care pathway and how to provide good social work at end of life	Sets out role social workers have at end of life and the specific contribution of specialist palliative care social workers	Used this document's objectives as framework for what social workers can offer
Core Competencies in palliative care social work (2014) European Association for Palliative Care's Task Force on Social Work in Palliative Care	Sets out values and attitudes, knowledge and skills for palliative care social workers	Valuable resource for social workers	Used competencies as a basis for what palliative care social workers can do Signposts to it for further reading for palliative care social workers
Report on Champions project (2014) Association of Palliative Care Social Workers	Identifies how to support social workers to work with specialist palliative care social workers and to improve end of life social work	Response from APCSW to need for social care champions in end of life	Helps Palliative Care Social Workers and Social Workers to act as champions Suggests palliative care social workers become champions as one of the actions
Common Core Competencies and Principles for End of Life Care, to support end of life strategy (2008) Skills for Care and Skills for Health	Sets out Common Core Competencies underpinned by values and knowledge	Aims to develop workforce across health and social care	Used this to consider themes that matter and checked social work's offer against these

Initiative	What this covers	How does this relate to social work?	How this resource responds
NICE guideline: Care of dying adults in the last days of life (2015) NICE	Covers evidence-based good practice in health care Provides recommendations for if someone is thought to be entering last stage of life	Includes communication and shared decision-making	Used this to consider themes that matter and checked social work's offer against these
NICE guideline: Improving supportive and palliative care for adults with cancer (reviewed 2014) NICE	Advice for those who develop and deliver services for adults with cancer about what is needed to make sure that patients, and their families and carers, are well informed, cared for and supported	States the role of social work within services and the importance of access to social workers	Used this to consider themes that matter and checked social work's offer against these
NHS England National Palliative and End of Life Care Network	Supports system-wide improvements and coordinate actions	Can be a resource for social work	This resource is shared with the network
Dying well at home: the case for integrated working (2013) SCIE	Sets out the evidence for why dying at home matters and how to achieve this	Recommends considering the role that social workers can play at the end of life States that social workers may well have the skills to support advance care planning and to assist with practical and financial problems	Used this to consider themes that matter and checked social work's offer against these
Current and future needs for hospice care (2013) Commission for the future of hospice care	Talks about demographic change and need to diversify, meet a range of preferences and show impact more	Does not specifically mention social work	Used this to consider themes that matter and checked social work's offer against these
A Guide to End of Life Care: Care of children and young people before death, at the time of death and after death (2012) Together for Short Lives	Guidance to support the care of the child at end of life, at the time of death and beyond. Provides detailed advice on how to support children and their families	Does not specifically mention social work	Used this to consider themes that matter and checked social work's offer against these

WORKING GROUP MEMBERS

Becky Chaddock

Association of Palliative Care Social Workers

Becky is Palliative Care Social Worker and Deciding Right Facilitator at Eden Valley Hospice, Carlisle. Deciding Right is a Cumbria wide programme to establish a standardised approach to early introduction of advance care planning for everyone. Becky has previously worked as a community social worker with older adults.

Anne Cullen

Association of Palliative Care Social Workers

Anne is Manager of Patient and Family Support at Princess Alice hospice, Esher. She has previously worked in services for children and young people, mental health and workforce development. She has a research interest in social work leadership.

Caroline Fox

Making Waves/OPEN FUTURES Research

Caroline works at the lived experience network Making Waves. She is the co-lead of the Integrated Research Group Open Futures at the Institute of Mental Health in Nottingham. She is a researcher and activist.

Julie Gosling

Making Waves/OPEN FUTURES Research

Julie is Training, Education Research lead of the lived experience network Making Waves and Joint Research Lead of OPEN FUTURES at the Institute of Mental Health in Nottingham. She teaches at both universities in Nottingham and is a committed community activist. She has advocated for and with people nearing end of life.

Jenny Latchford

Association of Palliative Care Social Workers

Jenny is a Specialist Palliative Care Social Worker at St Leonard's Hospice in York. She has a varied career in social work spanning 29 years and working mainly in multidisciplinary health and community teams. Communication Skills and Advance Care Planning are her areas of special interest and teaching.

Linda McEnhill

Hospice UK

Linda is Psychosocial Care Lead, Hospice UK and interim director of Care Services, St Joseph's hospice, Hackney. Linda is a palliative care social worker. Her particular interests are in extending access to palliative and bereavement care for people from marginalised groups and in ensuring the psychosocial aspects of care are given their rightful prominence in end of life care services.

Geraldine Nosowska

Former College of Social Work

Gerry is a practice improvement specialist for social work and social care, and Director of Effective Practice. She has previously worked in local authority community and hospital services as a social worker and manager. Her MA dissertation was on delays in take-up of Attendance Allowance experienced by people with a terminal illness.

Sally Paul

Association of Palliative Care Social Workers

Sally is Lecturer at the University of Strathclyde, School of Social Work and Social Policy. She was previously a social worker at Strathcarron Hospice in Stirlingshire. She currently teaches undergraduate and postgraduate social work students and is involved in research around palliative care, bereavement and loss, community engagement and practice development.

ACKNOWLEDGEMENTS

The working group would like to thank the Association of Palliative Care Social Workers, the former College of Social Work, the British Association of Social Workers and Hospice UK for their help in producing this resource.

We are also grateful to Hayward House, Maggie's, Nottingham, 'Shamrock's' family and survivors at Making Waves for making it possible for us to include the accounts of lived experience and, above all to the people who provided these. To see these in full please go to www.apcsw.org.uk

We acknowledge the contribution to this resource of previous work to improve palliative, end of life and bereavement care.

Our thanks also to all those who commented on the resource.