

Using evidence for change

What works to support care at home staff providing palliative and end of life care?

Evidence from local authority care at home staff



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Contents

Introduction	3
Key messages	4
Interview analysis	6
Staff experience of providing palliative and/or end of life care	6
Feeling proud	6
Work with partners and families	6
Time and continuity	7
Challenging experiences	9
Summary	10
Staff capabilities	11
Confidence in providing care	11
Communication skills	12
Enablement	13
Summary	14
Potential solutions	15
Knowledge into Practice support	15
Providing information	15
Practice based learning	17
Education and training	19
Areas for improvement	25
Provision of information about clients care needs	25
Multi-agency communication	27
Teams and team meetings	31
Bereavement support	33
Summary	35
A Specialist team?	37

Introduction

This report provides an analysis of interviews with 10 Social Care Workers providing care at home, and seven Home Care Coordinators (covering care at home) employed across the City of Edinburgh Council. The Home Care and Reablement Acting Depute Sector Manager invited relevant staff with experience of providing palliative and/or end of life care to volunteer to be interviewed, informing them that the ‘the main purpose of the interview is to understand the challenges that you face in supporting people with palliative and/or end of life care needs, and what forms of support and training might help’.

Face-to-face interviews were held in local authority social care office premises, and undertaken in staff time. Interviews were approximately 30 minutes in duration.

This evidence collation was carried out to complement the two other evidence reports in this collection that focussed on: 1) published research around this area of work; 2) improvement knowledge and learning.

Key messages

Care at home staff providing palliative and/or end of life care:

Are:

- Proud of their work in palliative and end of life care
- Providing much emotional and social support as well as personal care
- Working with clients with increasingly complex needs

Need to:

- Be confident in the care that they are providing
- Have good communication skills
- Enable their clients to do as much as they can for as long as they can

Would benefit from knowledge into practice support, in particular:

- More knowledge about palliative and end of life care
- Information e.g. on specific illnesses/conditions, pain management
- A specific phone line or phone link with a more experienced professional
- Opportunities to visit/shadow specialist palliative and/or end of life care providers e.g. hospices. Maggie's Centres.
- Training in palliative and end of life care, in paid time and face-to-face

Would benefit from service improvements, in particular:

- Improved information about clients care needs
- Improved multi-agency communication, in particular with nurses

- Multi-professional mutual respect
- Bereavement support for Social Care Workers

Interview analysis

Staff experience of providing palliative and/or end of life care

Feeling proud

Interviewees considered that caring for people who are dying is a privilege, and felt proud of the care that they provided:

- I've only worked with clients who are dying a few times. It's sad, upsetting, but it made me feel that I'd done something to help.
- I'm proud that I'm able to work with them in the last stage of their life.
- It's the last thing that you can do for someone – that's important.
- It's a privilege to provide end of life care, to share end of life with a person.

Work with partners and families

Interviewees noted that, although their work was for the client, with clients who need palliative care, or who are dying, it is impossible not to relate to their partners and families as well:

- I was working with a woman with dementia and her husband was dying of lung cancer. The office says that I'm only there for her – but I can't not be there for him. You can't separate it – I couldn't not make him a cup of tea, nor not listen to him. You need to involve the family. I couldn't discuss it [supporting the husband as well as the wife] in supervision.
- His wife relied on us for support, to talk to, and it took time for her to realise that he was going to die in two weeks: it's not just about personal care.

- I got the minister to come to the house to give communion – it was just a phone call, but it made a difference to them. Our work is much more than feeding and washing and giving drugs.
- As carers at the end of life we need to work with the family too.

Work to support partners and families takes more time than is allocated for the care session:

- I always make sure that the family or the spouse is OK – that can take an extra 5 – 10 minutes, but they've got needs too.
- I could give his mum quality time with him e.g. going out to get him a McDonalds, so that she had some respite from being his carer. I needed to provide regular updates and have regular phone calls with her. We got support for her on housing issues – put her in touch with VOCAL - she wasn't getting out of the house at all. It's the wee things that we can do, like getting the phone numbers for her. We just build in that time to what we do – but it would help if extra time to be responsive and flexible in end of life care was built into our slots and recognised. It's all about our relationships with him and his family.

Time and continuity

Manager recognition of this, and flexibility in managing time slots, is important:

- You can't not care for the family, and because we have a really good boss she lets us take the time e.g. to take them for a coffee.

Managers and social care workers who were interviewed all noted time dimensions in caring for clients with palliative and/or end of life care needs. There can be significant challenges in actually setting up end of life care packages:

- End of life care at home is not always possible because of availability of staff – we need 2 people for each visit to manage the equipment etc.

but in reablement teams we have an OT in each team so that really helps for managing the equipment. But it's not always already in place at home unless the person comes from a hospice, where OT things get sorted. If a client is coming from mainstream OT, then it can take weeks – so e.g. we can't give them a shower because the equipment is not there, or has not been assessed. That can't work for end of life care, because things need to happen quickly.

When a palliative and/or end of life care package is set up, it doesn't always provided enough – or flexible enough – time slots; even when the package is delivered through reablement teams:

- We need more time with them – and not time slots. It gets to 9.30 and I'm running out of the door – and she's dying! She might just need 10 minutes.
- They need to look at the time slots for end of life care – you can't put a time constraint on it: you need to focus on the person.
- I spent more time with her than normal; I just sat and held her hand.
- You need more time when working with palliative and end of life care clients; and you need to give the family that time – to listen to them, to let them go out for milk. At the moment I'm lucky – our boss really listens to us. I've become quite headstrong and assertive about asking for that time – and asking my boss to assign that next half hour to another carer. And I often get it! [The managers] might not be aware that dying clients need more time.

Interviewees stressed that clients with palliative and/or end of life care needs especially needed continuity of care – and were concerned that this was not always provided:

- There can sometimes be 4 x 2 carers going in each day – there needs to be continuity: not 8 different staff.

- There needs to be continuity of staff – that’s much more important than having specialist staff.
- There needs to be continuity of care – there needs to be the same carers for clients. That’s difficult for me as a manager, logistically. But training, resources, and awareness of the whole workforce would help.
- Sometimes clients [at end of life] do recognise you – you really need the same faces going in. There needs to be continuity.
- When someone’s off and you need to cover you can go into palliative care clients. You need continuity, especially in end of life care. You need to be there for them.

Challenging experiences

Managers who were interviewed noted that social care staff are providing much more complex and challenging care than they used to:

- They’ve come into this work from being home helps – and now they need to provide complex care.
- It can be very daunting for care staff – being there at their last breath.

Some interviewees noted that staff didn’t always know what palliative and end of life care is:

- It’s not always cancer – people think palliative care is all about cancer, but it’s all sorts of things, MS...
- We work with palliative care clients every day – but not clients at the end of life

Two interviewees, one a manager, and one a social care worker, described very distressing experiences:

- Carers can’t say that someone is dead because they’re not medically trained. They can’t tell the family that the person has died – they need to wait for a doctor. Even if it very obvious that a person is dead. I had a care worker who called 999 when her client died, and they told her to

do CPR, even though the client had been dead for some time, and obviously dead. There needs to be clear guidance for other professionals on the social care worker role – that might help to develop respect.

- We had the awareness that he was about to die, so should we give him time with his family or change him? We didn't know, so we changed him, and he choked and all this black stuff came up. If the nurses had talked to us we might have known. We had no-one to talk to and I had another client that I had to go to. We had to go to our next client – what could OOH do at Christmas time and after 9am: where would they find another worker. I was worried that he'd died because I'd moved him. If the nurse had been there she could have told us what was normal. And I couldn't speak to my manager until after the Christmas holidays, so me and my colleague had to support each other. We don't get any training, so we're working on our own initiative.

Summary

Social care workers and their managers' experiences of working with clients with palliative and/or care of life care needs indicate that social care workers:

- Work hard to provide the best possible care that they can, and are proud of their work in palliative and end of life care.
- Note that their work can be about providing more than 'personal care'; and that it is impossible for them not to relate to the partners and family of the person who needs palliative care, or who is dying. This can mean that the care worker overruns the allocated time for the session; and that manager support for this is important.
- Are working with clients with increasingly complex needs; and that they don't always know what palliative and/or end of life care is.
- Bad experiences when a client has died indicate that:

- Other professionals need to have clear guidance on the role of social care workers in working with clients with palliative and/or end of life care needs.
- Social care workers need:
 - To have a better understanding of end of life.
 - Effective management support when a client dies during a care session.

Staff capabilities

Confidence in providing care

The need for clients and their families to have confidence in care staff was stressed:

- We're working with very fragile older people, who are in pain all the time. We need to reassure them, they need to have confidence in us.
- You need to build a relationship with them, and then the person has confidence in you, the family has confidence in you, and then I feel confident.
- Sometimes it's the family that doesn't accept that [your client] is dying – and they don't want you there. So you need to get their confidence in you. Sometimes you need to be there for the family more – you can't not do it [for them]: they're there. It's not just one person at the end of life, it's the whole unit, the whole family.

Interviewees were reasonably confident in their abilities to provide palliative and/or end of life care:

- I've worked with a few folk at the end of their life and I've developed confidence, and empathy.

- You need to know that you're doing everything to the best of your ability.

However, they also recognised that whilst they had experience and were reasonably confident, new social care staff may not be as confident or able:

- You need to have social care workers who are confident. If I was working with a new recruit I'd tell them that it is important to remember that you're there for the client: you need to put your happy face on, even if they're in pain, depressed, crying. I'd go through what the person needs before we entered the house, and describe how I work. When I find out who I'm working with with a new client, I always phone them to prepare.

Interviewees noted the need for social care staff to have the right personal disposition:

- You need to be cheery, practical – not with a long face because they're dying. They don't want to see you miserable.
- You need to be the right type of person [to work with dying clients] – it's not just about the illness, you're dealing with their emotions.

Communication skills

The need to have good communications skills was emphasised by interviewees:

- To explore how best to meet the client's needs:
 - I give them their dignity and do my best to make them a comfortable as possible. You find out about how to do that by talking to the person – if they can talk.
 - If I was to advise a new worker I'd say go in with a gentle approach. It's all about listening and actually hearing and taking the time to hear and showing them that you've actually heard.

Be non-judgemental and don't talk over them, allow them dignity and never forget that it could be you.

- To be able to answer the questions that clients and their families might have:
 - I can communicate well, and that's the key to our job: when a client needing end of life care and their family they may have never experienced it before, so they will have lots of questions about medical care, the care that we can provide, other supports that are available, the equipment that they need to use e.g. for toileting. So we need to have a lot of knowledge – which we can have through our contact with OT, GPs, nurses (incontinence, district etc.). We need to know about managing incontinence pads, pain meds – and we need to have contact details for doctors and nurses.
 - You need to have good communication and empathy with the family, so that when they come to me with a question, I need to be able to find the answer.

Enablement

Interviewees also stressed the importance of enabling their clients to do as much as they could for themselves:

- It's all about allowing them [the client] to do as much as they can for as long as they can – so that they have some semblance of control, for example, drinking, shuffling up the bed.
- I always strive to deliver the best person-centred approaches so that I can feel confident and proud about making folk feel better with whatever little they've got left. For example, we encouraged [the client] to brush his teeth, to put a toothbrush into his hand and give him that independence. He could do nothing, and it inspired me to do more

about what I could do. I felt so proud to realise that even in the very last days of life you could still set goals and achieve them.

They noted that this can mean that they need to – and want to – provide more than ‘personal care’, which can mean that they need to be creative in managing their time allocations:

- What do you do when you see a client going down? You try to make her feel good ... wash and set her hair which she loves. But we’re supposed to be there only to make sure they take their meds. If they [the managers] knew....
- I don’t go by the book

Summary

Social care workers and their managers’ experiences of working with clients with palliative and/or care of life care needs indicate that social care workers:

- Stress that clients and their families need to have confidence in them; and that they need to have confidence in their own abilities to provide palliative and/or end of life care.
- Need to have good communication skills:
 - To explore how best to meet their client’s needs.
 - To be able to answer the questions that their clients and their family might have.
- Value their work to enable their clients to “do as much as they can for as long as they can”.

Potential solutions

Knowledge into Practice support

Managers and social care workers who were interviewed all said that they would like to know more about palliative and end of life care:

- You need to know about giving them choices about the end of their life.
- You need to be able to help them make choices, especially at the end of their life – spirituality is important.
- You need to be able to work with their emotions – when they're grumpy.
- Having the knowledge to be able to say to a client or a family that they can get information from XYZ. I had a client who had no idea about how to deal with the financial aspects, so I referred him to Marie Curie, Maggie's Centre, Macmillan – but I don't know what the difference is. We need to have knowledge and experience.

Providing information

Interviewees said that they would like to have more information about:

- I'd like to know more about the difference between end of life care and palliative care
- I'd like to know more about dealing with pain and their physical symptoms.
- The specific illness/conditions that their clients have:
 - I had a client with Motor Neurone Disease: we need to know how it affects them – changes can be sudden. So I had to educate myself on the internet.
 - Information would be good – especially about what the illness is: you're told, but you're not given enough information.

- We need to know the facts about the illness.
- We need to have more knowledge about the symptoms of illnesses so that we know what to expect.

Interviewees noted that clients are making more use of telehealth and telecare, and that they would like to have more information about this, so as to better support their clients:

- We have a great OT on our [enablement] team – she provides us with information about telehealth and telecare devices, so that we can support clients to use them.
- I'd like to know more about [telehealth and telecare]. We don't use it in care, but some of our clients have it.

The following were seen as a helpful way of providing some information:

- Leaflets:
 - Leaflets about end of life care would be good
 - Leaflets would be good.
 - Information leaflets would help – we could build them into our policies and procedures and make sure that staff read them every year.
- A phone help-line
 - A phone line to call might help.
 - It would be good if we could phone a Macmillan nurse.
 - NHS24 isn't good enough for palliative care: we need a specialist phone line.
 - A phonenumber could be good – sometimes we don't have the answers for clients, to help them with their fear.

- We need much more experienced guidance – a link worker at a hospice at the end of a phone.
- Apps would be welcomed by some interviewees:
 - It would be helpful to have preloaded information in apps which provide a way through using e.g. google.
 - An app would be good – that you could use with the family.
 - An app could help – I often use my own smartphone and google to try to answer their questions. I could imagine working with a client on their tablet looking for information.
 - I use my own phone, so I'm happy to use apps etc.

But not by others:

- An app won't work because you're not going to stand there with your phone when they die

Practice based learning

Several interviewees commented that they had previous work experience that helped them in working with clients who needed palliative and/or end of life care:

- I've been a nursing assistant, and worked in hospital discharge, and that helped me feel that I was doing a good job.
- It helped that I worked in a hospital before.
- I also do a night shift in a care home – some people there need palliative care.

Interviewees (managers and social care workers) would welcome opportunities to visit specialist palliative and/or end of life care providers:

- Visits to Maggie's Centre, hospices would help – going in to meet the nurses, going into wards.

- It would be good to have visits to hospices, Macmillan to see what happens. And how they deal with emotions, especially with the family.
- It would be great to give carers the opportunity to go to the Marie Curie hospice, or Maggie's Centre to observe, and get answers to the questions that we have.
- I set up visits to St Columba's and Maggie's Centre but there's still a lot that we don't know.
- The carers say that it's scary going into provide end of life care – but going into the hospice took away their fears: everyone look happy.

Opportunities to shadow more experienced staff would also be welcome:

- With hospice staff and nurses
 - Care staff are really good at dealing with families, but sometimes they are walking on eggshells and worried about mentioning death. They need to be confident enough to have these conversations, but they don't know what to say. How do they comfort a family who is watching them give the client a bed bath? They need practical hands-on training – maybe through shadowing hospice workers, visiting hospices.
 - Co-working, shadowing nurses might help. The care worker could see how the nurse answers awkward questions, for example, 'am I dying?', 'when will I die?', 'will I be in pain?' But we'd need to think about it from the perspective of the client – how would they feel if there were more staff/faces coming into their home.
- With more experienced social care workers
 - New workers could start by shadowing more experienced carers – it's not until you're out in the field that you understand it – the induction is all about rules and protocols, not about how you

actually do it. Training in basic nursing skills is important – how to deal with pressure areas, bed bathing, personal and intimate care, changing a bed whilst a client is in it. The induction training is all paper based – it's not good.

- There needs to be hands on training and shadowing – experienced care workers, new care workers and office staff.

One experienced social care worker described how she had been shadowed by new recruits:

- In January/Feb 2016 three new starts shadowed me for about a week. I had a lot of work experience, and I talked them through my job. There were some resources to allow for this – it's only going to happen if there are resources: it hasn't happened since. I gave them my phone number – I wasn't required to do this – and they still call me sometimes for advice.

It is important to note that this initiative was resourced (for a short time), and that the care worker put more effort into this role than was required.

Education and training

Interviewees would welcome training in palliative and end of life care:

- Training would be helpful
- We need adequate training.
- We're carers, but we do more than personal care. Its counselling ... I have a degree in psychology, so I know about loss and bereavement, and I'm a very experienced carer. But I'd like more training – is this correct way to this this? Where can I improve?
- Surely we should get the same training that Marie Curie workers get.
- You just need to learn about things on the job – about breathing, oxygen, equipment, beds. What about girls who are less experienced?

- For training you need to bring everyone together, take their experiences into account, talk about the guidelines and how they've dealt with the death.
- We need training so that it's not a harrowing experience; so that we know when to call for medical or nursing assistance.

One manager noted the training implications of the forthcoming requirement for care-at-home staff to be registered with SSSC (intended implementation date September 2017)

- I think all social care workers should have training in providing palliative and end of life care – especially in view of the SSSC requirements.

Specifically, interviewees would welcome training in:

- Physical aspects of palliative and end of life care:
 - I'm not a GP – I don't know anything about meds. But if you're working with palliative and/or end of life care you need to know more about meds, and the illness – signs and symptoms end of life. I'd like training in this.
 - Staff need training in mobility and pressure issues, intimate care, end of life care e.g. hydration needs, strategies for dealing client and their families in end of life care.
 - Treatment awareness e.g. aftercare after radiotherapy
 - Risks if they have an illness e.g. a cold
- Specific illnesses and conditions:
 - More knowledge about illnesses e.g. cancer, MS, motor neurone disease. We need more awareness, to know about the signs to look for
- Pain management:

- Training on understanding pain would help.
- We need to know more about meds – for example morphine drivers. I had a client where the district nurse had left drivers which were supposed to work for 4 hours, but they only worked for one – and I didn't have a contact number for the nurse. We're not trained in how to use these things.
- Meds training, esp at end of life and having to administer stronger and stronger drugs.
- Communication in providing palliative and end of life care:
 - My biggest training need is about how to deal with discussions about choices about end of life care.
 - Training on communication would help – how to say the right thing, how to answer their questions. It's never really the client themselves, it's usually their family.
 - Emotional and spiritual issues in palliative and end of life care:
 - I've had no training in palliative care or end of life care. I've had training in dementia, but that's different. I'd like to have training in it – how to deal with emotions.
 - Training on spiritual and emotional issues – especially at end of life – would help.

One manager stressed the need for training in holistic care:

- But they need training that isn't about the medical model – a client isn't just MS or a tumour: that person is a hillwalker etc. There needs to be training in holistic care, not just about the illness and meds. But there also needs to be guidance on meds – there are dangers in having untrained workers giving meds. What if a social care worker gives a client their meds, and then they die? We need carers who understand the human being as well as the process.

Another manager considered that “training needs analysis might help”.

One manager stressed the need for professional training, rather than relying on cascaded training through managers

- For palliative and end of life care we need better and more frequent training, especially about knowing what to expect. They can't expect home care coordinators to disseminate training on this – we don't have specialist training. We had a half day training session for home care coordinators and then told to provide the training to care staff and work through book. But we're not specialists, and it's much too much on top of our current workloads. It would be much better to work with hospices and to develop personalised training e.g. about the different reasons for palliative care.

Some managers stressed the need for managers, as well as social care workers, to be training in palliative and end of life care:

- As a manager, I could do with more training, and I'd like my manager to recognise what I do. For example, I was supporting the Choice programme for 10 weeks, and I was never once asked what it was about.
- Managers need to have the same training as staff e.g. on pain management. So that we have the same awareness as them.
- As a manager I've had a 2 day training course and a half day training course: It's not enough.

Managers and social care staff who were interviewed considered the various Marie Curie training courses that some managers and staff had been experienced were particularly beneficial:

- I was part of a Marie Curie training programme as a mentor, but that was cut before the year was through because there wasn't enough manager commitment (they had to provide time – 2 hours once a month – to support), so we only got 2 staff through. It was really helpful

in terms of understanding care plans, anticipatory care, confidence in talking about death, communicating with district nurses. One day training on palliative care isn't enough. The Marie Curie course was 3 months, involving lots of reading, assessment, tools to make staff think about things. I did it because I was mentoring staff through it. The Marie Curie course wasn't difficult: it was online and had an app so that people could access reading through their smartphones and read it on the bus etc. I booked them computers and helped them to log in so that they could do it here. It's intimidating to come in here to use the computers, so it would be much better if they could do it in a wee place with someone to help them to log in. They did it mostly in their own time, except a wee exam at the end of the course. The nurses use a lot of jargon, and the clients ask the care workers about what it means. That can make them feel very unconfident, but the 2 staff who have done the Marie Curie course now have knowledge of meds and illnesses, and can provide the clients and their families with answers.

- Some staff recently did the one-day Marie Curie course, and they loved it. It helped them to understand the difference between palliative and end of life care, and helped them to recognise that they actually have palliative care clients. It would be great if Marie Curie could provide hand-on mentoring, then they could learn by doing – shadowing a Marie Curie nurse for a day. It's all about understanding, knowledge and skills, and they could get that through shadowing. They could learn about coping, and what's available for end of life care. They would learn that things need to be quick. Home care coordinators as well as social care staff should do it. The key issue is backfill – but they have to do the mandatory training, so why not this?
- I did a Marie Curie course about end of life care. It was enjoyable – not morbid at all. It was all about involving the person. It was a half day course, with lots of people there, and they did small groups too. I got the time [from work] to do it, but I'd love to do more courses.

- I did the online Marie Curie course and the day course at the city chambers. It was super for giving us knowledge and understanding. We need to remember that people are still living, even though they're dying. I learned that palliative care isn't just about cancer; and that palliative care isn't about end of life care – it's about helping someone to live.

Some interviewees considered that online training would be helpful:

- I'd do an online course – I've done all the mandatory ones. I can focus more if I'm working individually. I'm happy to do assessed courses – you need the feedback to know that you're doing it right.
- I think an online course could cover the mandatory stuff.

Other staff considered that online training definitely would not work:

- Online learning physically scares them.
- Not all staff are comfortable with online training – it can be a bit of a tick box exercise. There needs to be more engagement.
- Online training wouldn't work: it is an ageing workforce who often can't use IT. We don't have any spare lap-tops for them to use. So it would need to be face-to-face training, hands-on and practical; cascading it via managers wouldn't work – I'm not a trained trainer.
- Training would help, but it would need to be face-to-face.
- I wouldn't do on-line training, but face-to-face – one off session, courses, assessed training would all be OK.
- The training would need to be in classes - I don't have a computer. But it needs to be about emotions as well – how can you get that from a computer?

Some social care workers thought that it would be impossible to train staff in providing palliative and end of life care:

- You can't train empathy.
- I don't think that training would work – you don't get training in how to be with our clients; we get training in how to use hoists etc.
- I just know what it is that people need – I don't know how you could train that.

Some social care workers who were interviewed said that they would be happy to do training in their own time:

- I would do training in my own time, especially if it was online. I'd like to know more about the illness they have.
- I would do training in my own time because I have a particular interest in palliative and end of life care.
- Of course I'd do it in my own time.

Others would not do it in their own time:

- It would need to be in paid time.
- I don't have time to do training in my own time.

Areas for improvement

Provision of information about clients care needs

Interviews indicate that managers and social care workers need more and better information about clients who need palliative and/or end of life care.

- Referral information does not always state that a client needs end of life care:
 - Sometimes we don't know if a client is at the end of their life unless it is stated in the discharge letter, or the GP or district nurse lets us know.
 - We get terrible information about clients, so I need the staff to go back to them in non-core times to go through the care plan.

- A standard referral template would be helpful, including
 - Has a discussion with the person taken place
 - What do they want the family to know
 - What does the person know
 - Is this included in the care plan
 - What to expect re diagnosis/progress re the care plan
- Normally we'd know if a client is end of life – often my clients come through St Columba's, so I have a good relationship with them.
- Social care workers are not always told that their client is having palliative care, or is dying; and if they are, they don't always know what this means:
 - I had one woman who died in 3 weeks – I wasn't told by my manager that she was dying.
 - I didn't know what to expect when I went in – I was just told that she needed palliative care over the phone. It would have helped if the office had explained.
 - We get basic information about our clients in advance, but it would be good to know more and maybe meet the client earlier. We learned about anticipatory care planning in the Choice project, and what a wonderful tool it would be to have information about a person's preferences etc.
 - It would help if they gave us more information about our clients.
- The quality of the care plan is important, and time to actually read the care plan:
 - I always read the care plan – that can give you a good idea.
 - We're not given time to read the books, so we just skim them and then check the meds.
 - The care plan is a great starting point, but then you need to talk to the client if they're capable of talking – or their family or the people round about them if they're not – about our role and what we do, about what they like, their preferences and interests.

Multi-agency communication

Managers and social care workers who were interviewed stressed the need to develop better multi-agency communication, in particular between social care workers and nurses:

- The key aspect is to get communication flowing from all agencies from day one.
- Communication with the nurses is the key: it needs to be good.
- The key thing is getting good working relationships with the nurses, and getting over that fear of talking to the nurses.
- They need to not put us in impossible situations – we need nurses to talk to us.

It is recognised that this can be challenging:

- It's really difficult to get immediate help because district nurses are out working all the time, so they can't answer the phone. So we need to go through NHS24.

But where improved communication is built into routine work, this is (or would be) welcome:

- Developing more effective written communication, through shared care plans etc:
 - Sometimes it works well with district nurses etc., but sometimes it's not. We need to work as a team – for example, by putting everything in the same folder in the client's home. We need to be able to read it as one book. Sometimes we need to make a lot of phone calls just to get the information that we need about a client – to answer family questions. It would be better if we shared information more.

- Nurses need to communicate better with care workers – they have their book, and we have our book: we need to know if they've made changes to the clients care e.g. meds.
- it would be good if they provided information on meds – sometimes there's no notes left for us on how to use e.g. how and when to use creams, patches.
- Joint visits, and getting to know each other can be beneficial:
 - My team struggled with joint working with nursing staff at first, but that's improved because of joint visits, getting to know each other, and generally closer working relationships.
 - We need to be able to work closely with the other folk going in – the Macmillan Nurses. We don't meet them unless they're in when we're in. We need small meetings with them, their phone numbers.
- One manager suggested that:
 - After a big and complex case we need to have a multi-disciplinary team meeting, including what we could do better.

Interviewees stressed the benefits improved multi-agency communication and ongoing contact in relation to specific clients, providing several examples of good practice:

- I work with the district nurses, palliative care nurses working with the client. There's lots of things that we need to know, so we're always asking them questions about the care that the client needs and giving them choices.
- I had a client who was dying, and I worked really closely with district nurses, Marie Curie nurses.
- It was a referral from the district nursing team, so they were involved before us. We got really good information from them, and the district nurse was really helpful to me about how to communicate with him. We recorded notes for each other in the communications books, and

the care workers and nurses talked to each other whilst we were in the house together.

- I had a client who died who was a younger woman. Her mum needed a lot of support. We liaised with her mum and the nursing team to ensure that he was as pain free and as comfortable as possible. It was all extremely emotional, and as a team we supported each other a lot.

Two interviewees, one a manager, and one a social care worker, described examples of poor practice in multi-agency communication:

- We need better relationships with other professionals – staff need to know when to call nursing staff e.g. about signs of end of life. I had one team who changed a client's [incontinence] pad, and then he died. They were worried that they'd killed him, they didn't know the signs of end of life, so they felt terrible. They called the district nurse earlier, and she didn't come out. They were made to feel stupid about asking questions, about asking for advice and support – so they need to be more assertive. Joint working would really help – if car staff could go out with nurses as a team to a client who needs end of life care. They could go in together twice a day, and then the care staff wouldn't feel daft about asking a question, nurses and care staff would have each other's numbers and they could phone each other.
- We were told that we were supported by district nurses, but he was dying and we phoned them for support, we were told that were there just to do personal care and just to get on with it. We didn't know what do to – it was our only source of support and we were denied it at the time we needed it.

Several interviewees noted that they did not feel valued by other professionals, and mutual respect needed to be developed:

- I've never been in a job where I've felt so de-skilled and demoralised. It because of the politics – you're 'just' a carer: no one actually says it, it's all about how you're treated.

- There needs to be respect, and an understanding that we're all here for the same aim. We have team meetings with the home care coordinators, occupational therapist, some office staff – you can say things, but that doesn't mean that they're taken on board.
- It's like a kick in the guts: we want to be professional, but we need the training.
- We have the knowledge, but not the professional recognition, so families don't take us as seriously as nurses. For example, a family insisted that we gave a client a bath. She was exhausted, and died two days later. We thought that a bed bath would have been sufficient, but the family didn't take us seriously because we're not seen as relevant, we're just carers. But we're there 80% of the time when nurses are there less than 20% of the time.

Training and professional development of social care workers was seen as a key way of achieving mutual respect by one manager:

- There needs to be open communication with other professionals – and social care workers need to be valued by other professions, such as nurses. If care workers were trained, they might be better valued because they would have a knowledge base.

One manager and one social care worker who were interviewed had been involved in the Choice project, which involved structured development of good practice in multi-agency communication:

- I was involved in the Choice project at Queen Margaret University. This was all about integrated health and social care for end of life care. It involved joint working with district nurses e.g. on signs of ageing e.g. on skin. I did a blog. There were 5 sessions with Marie Curie, we made a wall chart and tried to set up a drop in centre e.g. between 11 and 12noon when a district nurse would be available to answer our questions. But it didn't work because there weren't enough people on board. I think it would have been really valuable because it would have

let us discuss issues as they arise with a nurse, e.g. a client's leg colour. That would help us to feel confident. A phone line would work too.

Including other professionals in team meetings was mentioned by several managers and social care workers as a way of improving multi-agency communication:

- An impact nurse came into my team meeting to talk about the illness that one client has. This reassured the staff about what is normal, and when they should call in other professionals or dial 999. It really helped to develop relationships, and enabled care staff to phone the nurse for advice about things.
- We need to work holistically, so we need better communication with nurses, we need them at team meetings.
- We've had impact nurses into our team meetings, and I have good contacts with district nurses.
- As a manager, I'd like a nurse at each team meeting, so that would enable us to tap into other healthcare professionals.
- Could Marie Curie staff come to team meeting to provide some input?
- Could hospice staff come to our team meetings?
- It's difficult when you're seeing people in a lot of pain – it would help to meet with a Macmillan nurse.
- We need a medical or nursing person to support our team: if our manager doesn't know about end of life or palliative care how can they support us?

Teams and team meetings

Interviewees were all from Reablement teams, and noted that whilst they had weekly team meetings, 'mainstream' social care worker did not have team meetings:

- It is very difficult to get mainstream social care workers [i.e. not enablement team workers] together.

- Mainstream workers don't meet weekly, but we too. That makes it so much easier.
- Mainstream [i.e. not reablement] staff don't have any team meetings, agency staff don't either.

One manager described how he had tried to establish regular team meetings for mainstream staff:

- At Oxgangs [mainstream service] I managed to get a room for a couple of hours every month in the neighbourhood centre – they were very kind. Before then we'd had to meet in a café. We have monthly group supervision, talk about service changes, meds etc. We do it in their paid time, so we get maybe 4 social care workers every month – there are 30 staff overall, so we're rotating through the team. At first the staff didn't like it, they saw it is a 'greeting' meeting. The agenda is defined by issues coming up e.g. facilitating training in dementia care, and encouraging staff to do the training in their own time. It's different every month, and I'd like to invite folk to put things on the agenda, but so far it's too new, this hasn't happened.

Interviewees welcomed the weekly reablement team meetings, but suggested that there could be more focus on palliative and end of life care issues:

- It's the enablement team, so we don't discuss palliative care.
- It might help to have more briefings with the team so as to focus on which clients' needs are the greatest or the most urgent; and then to allocate one/two staff members. It could be like the huddles they have in hospitals, and ideally every day.
- For palliative and end of life care weekly meetings are paramount – that happens in reablement teams: we're all learning through the meeting, and sharing experiences.
- It would be good to have palliative and end of life care on the agenda for team meetings – and be able to talk about working with couples and families.

The way in which reablement work was managed was seen by interviewees as particularly appropriate in providing palliative and/or end of life care – although clearly this is not ‘reablement’ work:

- Generally palliative and end of life care is part of the reablement service. It’s very proactive, flexible, quick to respond. It has OT working closely with it. The mainstream service is much more difficult [for palliative and end of life care]: it’s difficult to refer to other parts of the service, like OT or social work; there are logistical issues about having team meetings, or in areas where there are fewer buses.
- End of life care is provided through reablement teams. That means that it can fit in with people’s needs. It’s all about getting people home.
- The reablement team is not really for end of life care, but reablement teams can adapt quickly – almost hour by hour. Mainstream teams can’t do that.
- Reablement teams have the privilege of being able to work with clients to define the time that they need from us – and this may be less than they need when they come out of hospital, so that gives us flexibility.
- If I’m running late, then I can just call the office, and I know clients who are OK if I’m running late. With out of hours cover, I’ve learned that I need to tell them that I need them to cover my last client, and not my next.

Bereavement support

Interviews indicated that there was little or no formal support for staff when their clients died:

- Where do you go when you’re told that a client’s died? What can you do?
- We’ve got a duty of care – but how can we provide care if we’re very upset? It’s like being ill ... and it might not hit you until after a client has died.

One social care worker had had no manager support when a client died; but recognised that managers need to be effectively supported by their managers in order to be able to provide effective staff support:

- I had a client who died in my arms, and I was just told to go onto the next client. I think it depends on you coordinator [how they react to a client's death]. The coordinators need support to support us – and I don't think they get any.

Managers who were interviewed noted the lack of policy and procedure for supporting social care workers who clients die, but generally recognised the need to provide support:

- I offer debriefing for care staff who have had clients who have died. I recognise that it's traumatic. It should be standard procedure when a client has died to bring the care workers straight off their shifts and into the office for debriefing. Care workers build relationships with their clients, so they are bereaved when they die. We need to give them compassionate leave if necessary – we need to show compassion to our staff.
- When a client dies they [the managers] always offer counselling – you become quite involved, so you need to talk about it.
- I always have a wee supervision session, and give staff time off to go to the funeral.
- Staff need to be supported when a client dies – they need to be directed to counselling. It's very emotional for them, and they need to have time off to cope – this isn't standard practice. Sometimes they might get half a day off.

Peer support is important to social care workers with their clients die:

- I get upset when people [clients] die – of course you get involved with them. We support each other. I could phone my line manager or talk about it in supervision.

- We need to be able to communicate with each other, especially about emotional issues. Some people get very upset when their client dies – you get so attached to them. You can't put up the barriers that they [the managers] tell you that you should [so that you don't get attached]. So we need to be supported when clients die. You feel a bit sad and empty, but proud that you've done everything right.
- Our end of life clients die, and our support depends on our rapport with our colleagues. We need to contact our coordinator who should be able to send someone out to cover for us, take us for a coffee. It always helps if you're with a colleague, we can support each other. You need to be able to say 'I need to gather myself, cry, be late for clients'; we need to meet up with a colleague and talk it through – I don't know what the policy is, no one does.
- We all support each other. I'm always on the phone to [my colleague] about how our clients are doing.
- I always give my [care worker] colleagues my phone number, especially so that they can call if there's an issue out of hours.

Summary

Social care workers and their managers' working with clients with palliative and/or care of life care needs indicate that social care workers would benefit from:

- Knowledge into practice support, in particular:
 - More knowledge about palliative and end of life care.
 - Information e.g. on specific illnesses/conditions, pain management in the form of leaflets and apps.
 - A specific phone line or phone link with a more experienced professional who could provide more information e.g. on specific illnesses/conditions, pain management.
 - The development of knowledge and understanding through direct experience would be welcome; in particular opportunities to visit specialist palliative and/or end of life care providers e.g.

hospices. Maggie's Centres. Opportunities to shadow more experienced staff would also be welcome, e.g. hospice staff, nurses, more experienced social care workers.

- Training in palliative and end of life care, in particular the Marie Curie training courses. Training may be necessary for the future requirement for care-at-home staff to be registered with SSSC. Training would be welcome in physical aspects of palliative and end of life care; specific illnesses and conditions; pain management; communication in providing palliative and end of life care: and emotional and spiritual issues in palliative and end of life care. Online training may work for some staff, but there's a clear need for training to be delivered face-to-face; and for training to be provided in paid time.
- Support for improvements, in particular:
 - Improved information about clients care needs:
 - More detailed referral information, in particular whether a client has palliative and/or end of life care needs.
 - Managers (Home Care Coordinators) providing Social Care Workers with more information about their clients, in particular whether they have palliative and/or end of life care needs.
 - Improved quality of client care plans.
 - Improved multi-agency communication, in particular:
 - With nurses
 - Built into routine work, e.g. shared care plans and joint visits to clients.
 - Having regular multi-agency team meetings.
 - The development of respect for the work of Social Care Workers, for example through training and professional development.
 - Providing bereavement support for Social Care Workers, including effective policies and procedures for supporting staff when clients die, including provision of manager support.

A Specialist team?

Some interviewees considered that staff should be given the choice of whether or not to work with a client with palliative and/or end of life care:

- I would do it again, but I think you should have the choice whether or not to do palliative care.
- It isn't for everyone: it depends on their life experiences
- You should get the choice of whether to do palliative and end of life care – it's not for everyone.

A key challenge in providing staff with a choice is that managers don't always know if a client has palliative and/or end of life care needs; and clients who have palliative care needs may progress to end of life needs:

- It's not for all care workers; they shouldn't all be expected to do it. But we're not always told in advance if a client needs palliative or end of life care.
- Not everyone's cut out to work in this – some people are frightened, so it would be good to have the choice. The problem is that you don't always know in advance.
- I don't think that all carers could do it – I suppose you could say to your manager that you don't want to do it. But you could have an elderly client that progresses to palliative care.

One social care worker considered that training might be the key to ensuring that all staff could provide palliative and end of life care:

- I definitely don't think that it's for every social care worker – you need to get the right social care worker. Or maybe it's about training? They need to know that it's about more than making a microwave meal, or patting their head.

Some interviewees consider that there should be a palliative and end of life specialist team:

- I think it would need to be a specialist team – some care workers have said it's not for me.
- There needs to be a specialist team: we need to get a choice because not everyone is comfortable.
- Specialised teams would be the way forward – with carers, managers and office staff: there's too much emphasis on the generalist worker.
- I think that there should be a separate specialist team which is trained.

One manager considered that a specialist team may work, but could lead to high staff turnover:

- A specialist team would be fabulous, but I'd worry about the high emotional toll on the team, and that there might be a high staff turnover. They'd need to be emotionally resilient – but hospice staff do it. I've never come across a social care worker who has worked with a client who has died who has said 'never again': they've always said that they've felt OK that they've helped a person die well – it's been a positive experience.

Another manager suggested that an 'informal 'specialist'' team might be the way forward:

- It might be appropriate to develop an informal 'specialist' team of social care workers for palliative and end of life care.

One social care worker and one manager who were interviewed considered that all social care workers should provide palliative and end of life care:

- I think we should all be expected to do end of life care.
- It should be part of all social care workers jobs, but if they did it all the time, it would be very intense, so give them all the experience. Once they've experienced a death, they know how to cope with it.