
USING EVIDENCE FOR TRANSFORMATIONAL CHANGE

**FOR HOMECARE WORKERS AND SERVICE USERS IN
PALLIATIVE AND END OF LIFE CARE : MAY 2017**

*...it's a privilege to
provide end of life care
- to share end of life
with a person*

This project brings together evidence from three linked reports from the Networked Evidence Search and Summary Service - *Supporting Care-at-Home staff providing palliative and end of life care: 1. Summary of Published Research Evidence; 2. Report of Interviews with Practitioners in Edinburgh City Council; 3. Learning from others: summary of Improvement Knowledge.* In your own words, the key message from all these reports is that ***it's a role to be proud of.***

CHALLENGES IN THE CURRENT SYSTEM



The role is emotionally and practically demanding for homecare workers, yet currently there is often little or no training or support:

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.

They've come into this work from being home helps — and now they need to provide complex care.

WHAT NEEDS TO CHANGE?



BETTER KNOWLEDGE ABOUT...

- *The difference between end of life care and palliative care.*
- *Dealing with pain and their physical symptoms.*
- *Mobility and pressure issues, intimate care, end of life care e.g. hydration needs, strategies for dealing with clients and their families.*
- *Meds [medicines] — for example morphine drivers ... especially at end of life and having to administer stronger and stronger drugs.*
- *The symptoms of illnesses so that we know what to expect.*
- *Treatments ... e.g. aftercare after radiotherapy.*
- *Telehealth and telecare. We don't use it in care, but some of our clients have it.*
- *Giving choices about the end of their life.*

BUILDING SKILLS, BEHAVIOURS AND VALUES IN...

Relationship-based care:

- *You need to build a relationship with them, and then the person has confidence in you.*
- *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.*

Empathy:

- *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*



Note: All text in *black italic* is a direct quotation from a practitioner.



them dignity and never forget that it could be you ... You need to be able to work with their emotions ... Spirituality is important.

Holding challenging conversations:

- *How to deal with discussions about choices about end of life care ... how to say the right thing, to answer their questions.*

Holistic, person-centred care:

- *We need carers who understand the human being as well as the process.*
- *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.*

Enablement:

- *It's all about allowing them [the client] to do as much as they can for as long as they can.*

BEREAVEMENT SUPPORT

- *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.*

MULTI-AGENCY WORKING

Communication and partnership:

- *The key aspect is to get communication flowing from all agencies from day one.*
- *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 ... Joint working would really help — if care 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.*

Mutual professional respect:

- *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.*



INFORMATION & KNOWLEDGE

- **Information leaflets about end of life care** would help — we could build them into our policies and procedures and make sure that staff read them every year.
- **A phone line to call** might help.
- **An app¹** 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.
- **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?
- We learned about **anticipatory care planning** in the Choice project², and what a wonderful tool it would be to have information about a person's preferences etc.

LEARNING & DEVELOPMENT

- **Shadowing, mentoring:** It would be good to have visits to hospices, Macmillan to see what happens. And how they deal with emotions, especially with the family.
- New workers could start by shadowing more experienced carers — it's not until you're out in the field that you understand it.
- **Practical skills training:** 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.

- **Sharing experiences:** You need to bring everyone together, take their experiences into account, talk about the guidelines and how they've dealt with the death.

SERVICE IMPROVEMENT

Multi-agency communication processes and documentation:

- 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.
- 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 **small meetings** with [other professionals], **their phone numbers**.
- After a big and complex case we need to have a **multi-disciplinary team meeting**, including what we could do better.
- I'd like **a nurse at each team meeting**, so that would enable us to tap into other healthcare professionals

Bereavement support:

- **Debriefing and supervision:** I could phone my line manager or talk about it in supervision.
- **Peer support from colleagues:** 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.

1. Healthcare Improvement Scotland will launch an Anticipatory Care Planning app in May.

2. See Summary of Improvement Knowledge for report of this project run by Queen Margaret University in 2015.