



Person centred approaches to end of life care

The story of Bert his family and his carers

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The beginning of person centred support

- What is important to Bert and for Bert?
- What is our role in what is important to and for Bert?
- Meeting the needs of others, friends, housemates, staff, family?
- Physical, dying process and meeting terminal phase needs?
- What about care planning/advance care planning?
- Other service users – frightened by the dying process and remembering past experiences?
- Checking on the non-verbal communication ?
- Close friendships will change?
- Responses to the experience of someone dying in the home?
- Ethical issues will raise themselves
- Physical process of dying and the ways to meet Bert's needs – how long is the terminal phase?
- Disease trajectory and advance planning?
- Staff role and who does what – communication and care planning?

Staff

- Feeling helpless – what can I do?
- Managing fear – Bert, housemates, sisters, staff
- Pain assessment/ management – DISDAT
- Boundaries
 - what's my role?
 - what's my responsibility?
- Support for staff and tenants
- Supported living comes under Dom Care regs, therefore whose responsibility is health and emotional support?

What do we like and admire about Bert?

- His twinkly eyes
- He puts his head on your shoulder
- The way he looks at you
- His smile
- His quiet spirit
- A kiss on your top (head) when doing his shoe laces
- His mischievous spirit
- Helping and interested when cooking – nose in the pan
- Puppy eyes
- He watches and observes keenly
- Bert lights up from the inside when he sees his family

Important to

- Eating what he wants when he wants
- Cigarettes
- George
- Sisters
- Regular visits to sisters
- Family
- Jenny
- Cakes
- Going for a drive
- Company
- Music/CDs – tapes as he calls them
- Calm – listen to me
- People who he is familiar with
- Being supported by people he trusts
- Going out – to carnivals for example
- Horses and animals
- Watching football on TV
- Chocolate
- Garden, fresh cut flowers
- Songs of Praise on the TV
- Be funny, have a joke and sense of humour
- Back rubs

Important for

- Eat well
- Stop smoking
- Own space
- Keeping happy/content
- Retain family atmosphere
- Skin care where possible
- Longer, better staff handovers especially as illness progresses
- To do things at his own pace
- Have nice things to eat
- To take his medication
- Dignity
- Family –sister
- One to one quiet time
- Calm, confident support to be and act as normal as possible
- Be funny and humorous
- Sense of humour, craftiness
- Having support he likes and trusts

What does best support look like?

- One to ones
- See his sisters
- Being with Geoff
- Effective listening
- Regular support staff
- Good pain management
- Support with medication
- To enjoy/eat his favourite food
- Continue to feel safe in his own home
- To encourage longer breaks between cigarettes
- To have support around him from people he knows
- Staff appear confident when supporting Bert when poorly
- Going on holiday – 1,2, or 3 nights with whom Bert wants
- Going out when able to in a car, to go for a drink
- Spending time with the people he knows
- Vehicle available regularly
- Good planning

Advance care plan

What?

Who takes the lead?

- Health Action Plans
 - Each care domain listed
 - Pain/Breathlessness
 - DISDAT tool communication chart
 - Hand held fan
 - Calming massage
- Community LD nurse
 - District nurse-patches
DN Hand held fan
 - Community LD nurse and staff team

Advance care plan

- Source wheelchair
 - **J to progress** - Red Cross
- Bert to have access to lease car
 - **C B to investigate**
- Offer opportunity for Bert's sisters (family) to spend more time together
 - **J to ask/check**
- Check Bert's understanding of what is happening to him - does he wish to share this information?
 - CNLD and familiar staff member to work with Bert

Advance care plan

- Communication agreement amongst team ➤ Team leader
- Communication with other tenants – keep current strategies at the moment ➤ Team leader to monitor
- Staff to have training (if they agree) individual choice ➤ Hospice with nurses
- Supporting other tenants signs to look out for:-taking to bed, talking about death and previous deaths showing an acknowledgement of 'dying' ➤ Team focus meetings

Outcome

- Bert died at home with his family and friends
- He was comfortable and died with dignity
- Bert's health needs were anticipated and met
- His friends and family were well supported, their needs were anticipated and communicated
- Bert's life until the moment he died was fun, active, spiritual and just how he like it.
- The staff were supported by professionals who anticipated their needs and acted on them
- We would do this again!

The learning

- End of life care in learning disability services is multifaceted and so can be confusing, anxiety provoking, overwhelming and simply too much.
- People with learning disabilities may not always be able to talk openly or understand what is going on and so can be subject to practice that will cause them fear and distress.

Person Centred Thinking

- Supports the person who is dying to be involved no matter what.
- Helps people sort out the confusing and conflicting priorities of what's important to a person, for a person together with what best support looks like.
- Brings about action on care planning that is focused on the person and people around them
- Gives confidence to people who are making decisions that they doing the best for the person.
- Makes expectations realistic
- Makes sure the right people are doing the right thing at the right time for the right reasons.