

What can I do?

Practical messages for
front line workers

Be led by
the individual's
wishes:

Doing:
Working together,
communicating
and sharing

Attitude:
Value other people,
recognise their
contributions and
expertise



Be led by the individual's wishes

1. Listen to the person and their carers, create opportunities for them to express their views and concerns, understand how their culture and lifestyle affects their choices and how they wish to be treated.

Building the pyramid

Working together for good end of life care. Like any good care and support, working with someone at the end of their lives means creating a team of people around the individual, and working together to meet the priorities, needs and wishes of the person.





**Doing:
working together,
communicating and
sharing**

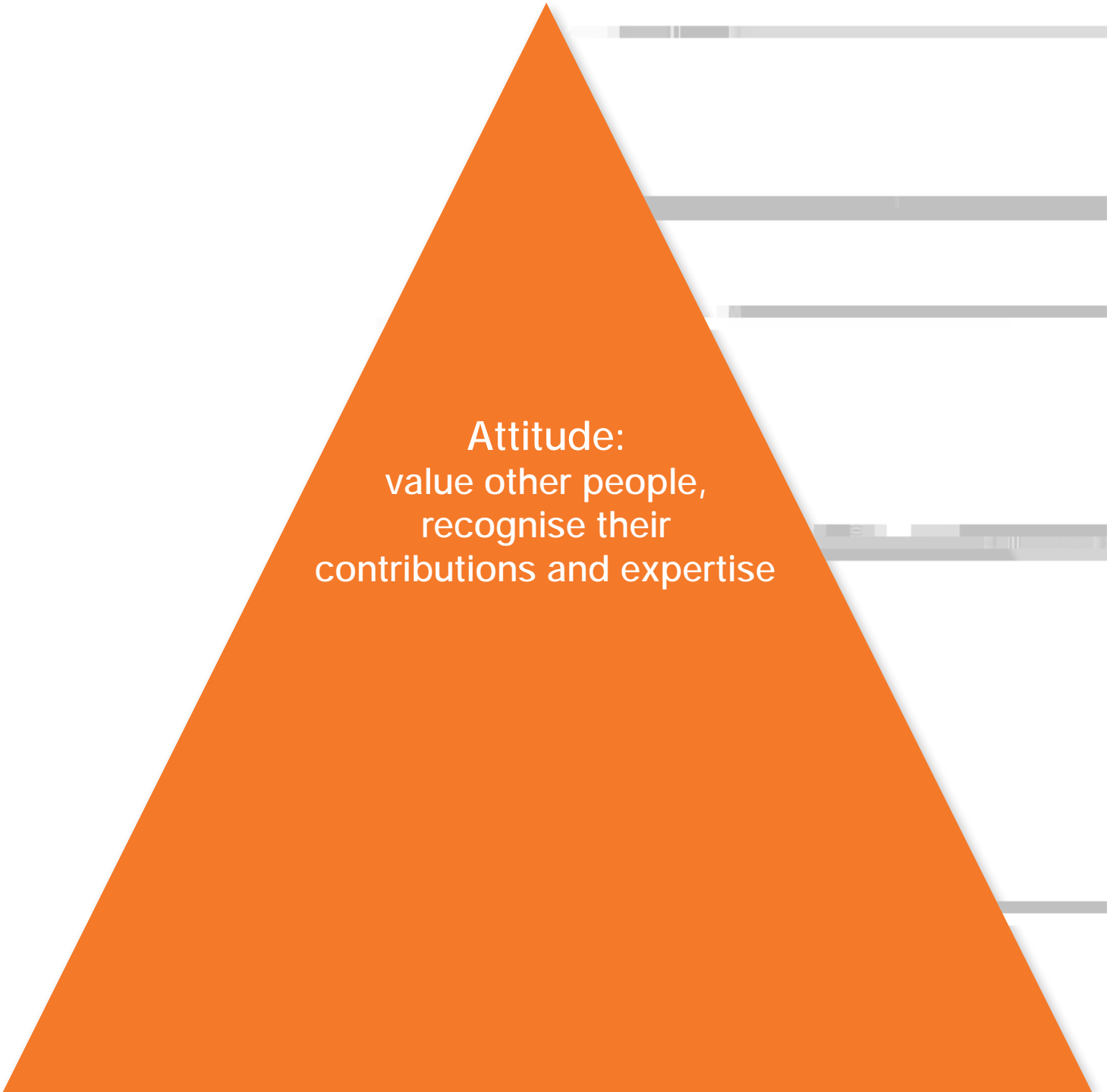
2. Care plans developed around the stated priorities of the person, kept up to date, and shared across the care and support team. Goals are clear, roles understood, and there is a named co-ordinator.

3. Information important to the person's care and support is shared as appropriate and up to date. Everyone including the person and their carers, knows and understands about changes and how they affect the care plan.

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There are many different agencies that come together to support and care for someone who is dying. This is likely to include social care and health workers, and may also include people from other settings. To make sure that the care and support is the best it can be the person, with their family and carers, must be at the heart of all planning and delivery, with their care and support co-ordinated around their identified needs and priorities.

The messages for practice laid out below are the result of a series of discussions between carers and practitioners from different social care and health settings. They arose from what people said about their own experiences, and what they told us mattered most. They are all things that can be incorporated into daily practice, and make a difference to the experiences of people using care and support services.

1. Listen to the person and their carers; create opportunities for them to express their views and concerns. Understand how their culture and lifestyle affects their choices and how they wish to be treated

- ✓ Be sensitive to the situation, explain things clearly and fully, taking account of the emotional impact of the person's situation. Find out what the person already knows, and establish what else they want to know. Check that the person has understood what you say.
- ✓ Good communication means listening for cues, and making opportunities for people to talk to you about how they feel if they wish to.
- ✓ People's priorities will be shaped by their lives: their culture, their relationships, their religion, lifestyle, occupation and other things. Listening to people means giving them the opportunity to talk about all of these things and from this let you know what matters most to them.
- ✓ When people don't feel listened to, when they find themselves being asked the same things many times, or when they cannot find out what they need to know, it can lead to frustration. This can affect how people behave, and the way in which they communicate. As a worker it is very important to find out why someone is frustrated and try to help, rather than react to their immediate behaviour.



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4. Value and understand everyone's role and contribution (the person, their family and carers, colleagues)

- v People are experts in their own lives, and should be central to any discussions; all plans should be shaped by what they (and their carers) see as the most important things. This will include their treatment and end of life care needs alongside the choices about the way they want to live, and the way they want to die.
- v Be clear about your role and responsibilities, make sure others know this. Find out about what other people are doing and what their expertise is. Remember sometimes "surprising" people become very important in someone's care and support. (For example the individual may build a trusting relationship with a cook or a gardener).

5. Support each other (the person, their family and carers, colleagues), listen, share expertise, be comfortable asking for support or information.

- v If someone wants information you can't provide (for example detailed information about their condition) make sure you know where or who to signpost them to. Use the expertise of other people in the care and support team to help you find out.
- v Sometimes people just need to be listened to, to voice their concerns and worries. This is an important part of working with people at the end of their lives, and of working with their families and carers. Don't "shut people down" if they try to talk to you. If you find yourself out of your depth, pass your concerns on to your manager.
- v Working with people who are dying can be an emotional experience for workers too. Don't feel uncomfortable about asking for support. Some employers can offer more formal support if that is needed, or you may want to talk to members of your team.
- v Colleagues can be a very important source of support for workers, be sensitive to how people less experienced than you may be feeling, let them talk about how they are feeling.

6. Use ordinary language and speak in ways that are easily understood, taking account of the situation and the person you are talking to.

- v Speak plainly using everyday language, avoid jargon.
- v Make sure you know about any aspects of the person's life that will affect communication (e.g. dementia, hearing impairment, language, culture) and how you can work with this.

