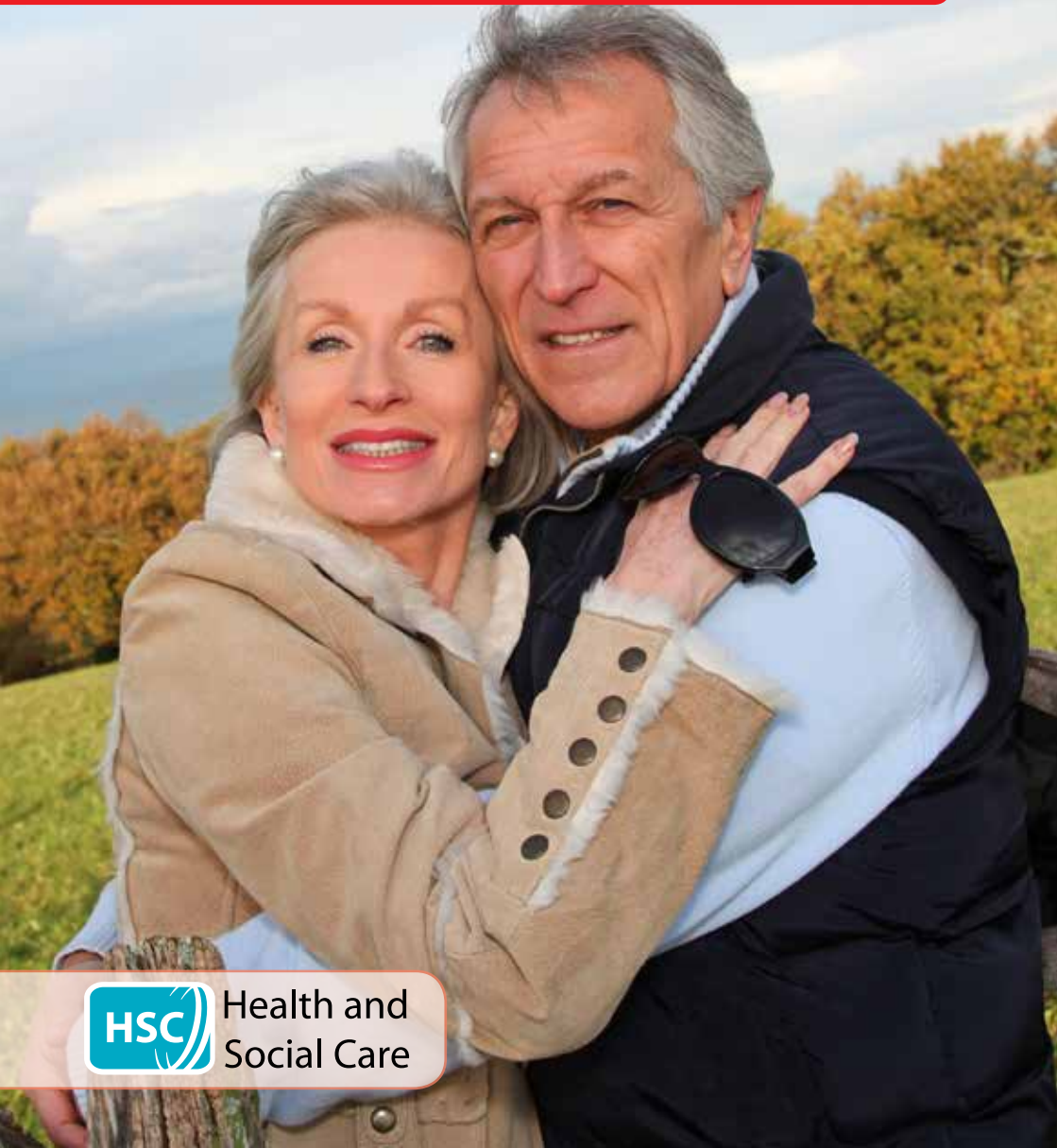


# Talking about risk and dementia



Health and  
Social Care





## Why is communicating about risk important?

We all come across risks in our everyday lives.

Living with a dementia can, for certain people, mean being more likely to face risks in daily life. These risks might include getting lost if out and about alone, loss of self-confidence or having an accident in the home.

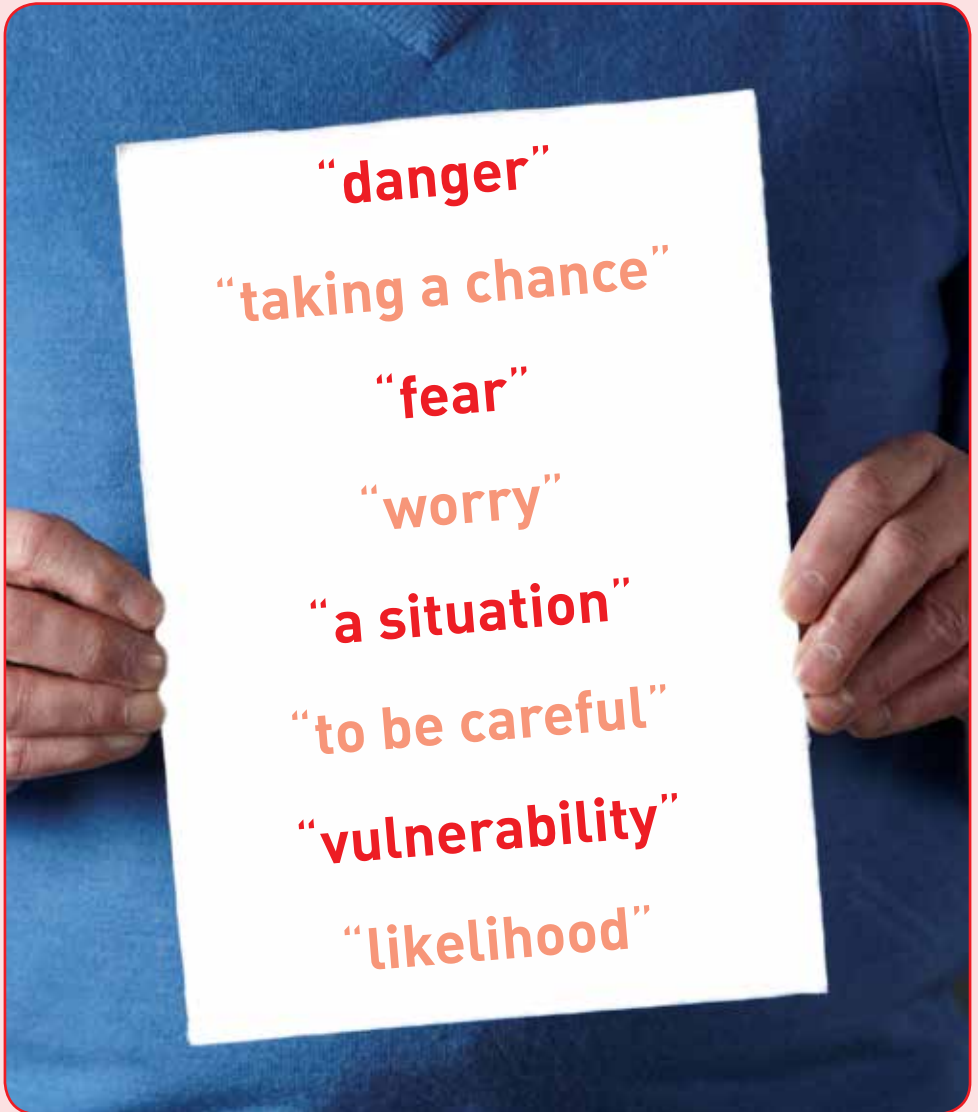
Risks can change over time and will depend on individual circumstances, such as the progression of a dementia, other health conditions and available support.

Risk communication means sharing information and feelings about risks and the benefits of different choices. For a person with a dementia these choices might relate to their health care, their social needs or their daily living activities. To make informed decisions in everyday life it is important that we are aware of the possible benefits and possible drawbacks of the different choices available to us.

This booklet was prepared using information from interviews and group discussions with people with a dementia, their family and carers and health and social care practitioners working in dementia care. It offers some practical guidance on making choices about risk and safety.

# What is risk?

Risk can mean different things to different people. Our ideas about risk will depend on things like our life experiences, personalities and individual circumstances. People will often have different ideas about which risks it is safe to take and which risks worry them the most.



# Living with risk

Risk will often make people think of negative things like harm and danger. However sometimes it can be worthwhile to take a risk.

Positive risk taking is about taking a balanced approach to risks. Positive risk taking recognises that sometimes taking risks can have benefits, while not taking any risks can be harmful in itself. For example, if a person with a dementia stays in the house all day, they may not be as likely to get lost or have a fall but they might be at increased risk of becoming socially isolated or depressed.

Positive risk taking involves:

- **weighing up** possible benefits against possible harms of taking a risk;
- **communication** to share ideas and feelings about these benefits and harms;
- **supporting** people with dementia to live well and maintain a good quality of life.

***“It’s really important that you can be independent but safe”***  
(person with a dementia)

***“Risk is not to be avoided. It is to be managed”***  
(family carer)

***“If you don’t take a chance you get nowhere!”***  
(person with a dementia)

***“Our role is not to come in and dictate to people what’s acceptable or what’s not. It’s about supporting them in what they want to do and keeping them safe”***  
(professional)

# What sort of risks might people with dementia and families talk about?

Most things that we do in our everyday lives will involve some risk.

People with a dementia and their families are often making decisions where they have to think about risks and safety. These decisions might include whether or not to:

- go out walking alone;
- keep driving;
- manage medications independently;
- keep up a hobby such as gardening or woodwork, or keep socialising;
- use a cooker;
- look after grandchildren alone;
- attend a day centre;
- use a variety of safer walking technologies;
- travel abroad.



Sometimes these decisions relate to things that might happen in the future, for example moving into a care home (see the *Dementia and moving to a care home* booklet). It is important that people with a dementia are involved in these decisions and given opportunity to share their ideas and wishes, including their wishes for the future.

To make decisions about risks, people with a dementia can talk to their families/ carers and to professionals such as social workers, occupational therapists, nurses, speech and language therapists, voluntary organisations or their GP.

Health and social care professionals can talk about different options to help manage risk. You might wish to talk to:

- an occupational therapist about changes and adaptations to the home (for example alarms and sensors or support rails) and aids (such as mobility aids and tracking watches);
- a doctor or nurse about medications;
- a social worker about social care supports and options such as social groups, supported housing and residential care.





## **Useful things for a person with a dementia to think about and talk about when making decisions about risks**

Before making decisions about risk and safety it is good to take some time to think about the different options. Below are some useful things for a person with a dementia to think about and talk about when making decisions about risks:

- What are the different choices available to me? For example keep going for a walk alone, give up walking, ask a friend or family member to go out walking with me or wear an electronic tracker when I go out walking.
- What would this decision mean for my safety?
- What would this decision mean for my quality of life and happiness?
- Is there anything that concerns or worries me about this decision?
- What supports are there if I decide I want to keep doing something that might involve some risks?
- Who can I talk to about this? For example family members or a health and social care worker.



# Practical tips when talking about risks and making decisions

The following tips were shared by people with a dementia, their carers/family and health and social care practitioners:

- People with a dementia should be supported to think about risks for themselves rather than being told what to do.  
*"I don't like to be treated like a child. I am quite happy to be independent, but sensible"* (person with a dementia)
- It is important to be aware of the individual's personal history and how this may make them think about risks – for example their job history, personality and experiences.  
*"We might go into a house and think 'gosh that's wild risky' [but] they might have been doing it all of their life"* (professional)
- Removing all risks for a person with a dementia (or for anyone) is not possible.
- When making decisions about risks think about the possible benefits (positives) of taking the risk as well as possible harms (negatives).
- Think about how likely the risk is to happen. Some of the risks that worry people the most might actually happen very rarely.



- Choose a good time to talk about risks and safety – some individuals find that there are certain times of the day when they feel more confident making choices.
- Give the person with a dementia time to think before making a decision.  
*“You see I am trying to make a decision but there's millions of things going through my head too”* (person with a dementia)
- If you are worried about a person with a dementia, choose the right time to sensitively talk through the reasons why you think it may not be safe for that person to continue with a particular activity.  
*“If it makes sense to me then that's fine”* (person with a dementia)
- Discussing possible risk scenarios might be helpful, for example talking about what might happen if a person with a dementia keeps driving.
- If professionals are using words and phrases that are not meaningful to you, ask them to explain things in another way.
- Make some short written notes after the discussion as a reminder of what was talked about and what was decided.

## Summary

Living well with a dementia does not mean never taking any risks.

When making decisions about risk, it is important to take a balanced approach. There can sometimes be benefits in taking a risk.

If you have a dementia and are worried about risks or safety, talk to a family member/carer or professional about your concerns and come up with solutions together.

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# Useful reading

Risk Communication in Dementia Study website. [www.socsci.ulster.ac.uk/irss/risk.html](http://www.socsci.ulster.ac.uk/irss/risk.html)

Alzheimer's Society. Safety in the home. 2014. Available online at [www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=145](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=145)

Manthorpe, J. and Moriarty, J. Nothing ventured, nothing gained: Risk guidance for people with dementia. London. 2010. Department of Health. Available online at [www.gov.uk/government/publications/nothing-ventured-nothing-gained-risk-guidance-for-people-with-dementia](http://www.gov.uk/government/publications/nothing-ventured-nothing-gained-risk-guidance-for-people-with-dementia)

Morgan, S. and Williamson, T. How can 'positive risk-taking' help build dementia-friendly communities? York. Joseph Rowntree Foundation. 2014. Available online at [www.jrf.org.uk/sites/files/jrf/Positive-risk-taking-dementia-summary.pdf](http://www.jrf.org.uk/sites/files/jrf/Positive-risk-taking-dementia-summary.pdf)

Sedgewick, R. Communicating effectively with a person living with a dementia. Public Health Agency: Belfast, 2014. Available online at [www.publichealth.hscni.net/publications/communicating-effectively-person-living-dementia](http://www.publichealth.hscni.net/publications/communicating-effectively-person-living-dementia)



## Public Health Agency

12-22 Linenhall Street, Belfast BT2 8BS.  
Tel: 0300 555 0114 (local rate).  
[www.publichealth.hscni.net](http://www.publichealth.hscni.net)

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