



Dementia Toolkit – Stay safe and well

# Rethinking risk



**Dementia Toolkit**  
Living your life with hope



## Stay safe and well

### Rethinking risk

Risk is part of all of our lives and it is important to recognise risks in order to stay safe and well. However, a dementia diagnosis can make some people have a bigger fear of risks or see things as riskier than before.

In this booklet we:

- explore what risk means for people with dementia
- explore what risk means for carers of people with dementia
- provide some strategies for dealing with risk for each group



**I've had some anxiety as I don't want to take risks and put others in danger. I've got to be more cautious which curbs my personality.**

A person with dementia telling our researchers how they felt during the pandemic



## We need to talk about risk

Risk came out strongly as a topic of interest as we created this toolkit. Carers worry about risk. People with dementia want to still be able to take risks. But is anyone talking about it?

We held a discussion about risk to try and better understand this issue. We split our discussion into three topics:

- What does it feel like if people don't allow you to take risks?
- How do other people see your level of risk?
- Do you think about risk and how do you manage it?

We have created a video for each topic which you can watch in full on our website. An extract from each video is provided below:

### What does it feel like if people don't allow you to take risks?



Chris, a person with dementia, says

**"The risks should always be there. If you don't have risk in your life, then life really loses an awful lot of its attraction. Because again, it goes back to looking forward to things, doesn't it, and if you enjoy doing something and then that's taken away from you, then that's another step in the wrong direction isn't it."**





## How do other people see your level of risk?



Keith, a person with dementia, says  
**"Often you're reminded of the don'ts rather than the do's . . . the negativity is what's constantly reminded to you, which I think is wrong."**



## Do you think about risk and how do you manage it?



Jane, a former family carer, says  
**"It's about a trust, I suppose, between the carer and the person you are caring for ... that you will help them to do as much as they can, but the trust that they will ask for help when they need it. And that's really important"**



Jacqui, a person with dementia, says  
**"I do monitor or . . . evaluate my own risk. And I do it on a regular basis because the time will come where I might have to say "I will need a carer to come in" or "I'll need more support."**



Risk isn't just about protecting people from a physical threat. This topic also involves

- having confidence to keep doing things and trying new things
- having choice and control over what happens in your life
- feeling connected to your identity

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**He is vulnerable, though, so it's weighing up the risks versus the benefits.**

**It's impacted my confidence in seeing other people as I'm having to assess risk. Not seeing friends has been difficult, no walks with them.**

**Within the scale of risks and so on, it seemed better to risk missing the blood test than going into the hospital.**

Three carers speaking to our researchers about the COVID-19 lockdowns

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## Carers negotiating risk

Look at the quotations on the previous page: carers think a lot about risk. However, there are different types of risks. We are used to thinking in terms of physical risk, but what other risks might carers need to be aware of?

We spoke to carers who shared their experiences of risk when supporting a loved one living with dementia. You can watch the full video on our website. Here are some extracts from these conversations.



Suzanne Mumford, Head of Dementia Care, Care UK, says

**"But that fear of walking away: are they going to be safe? Are they going to fall over? Is the next phone call I'm going to have from a paramedic or from a hospital saying they've fallen and broken a femur? . . . so that fear is very, very real."**



Jane, a former family carer, says

**"You can become really overprotective. So you want to do everything for them because, every time they get up there's a risk that they could fall over. But what you forget is, the more times you don't get them up, the more likely they are the next time they do get up to fall over, because they've lost that strength . . . so you're adding risk shall I say"**



There are a lot of emotions involved in caring for a loved one with dementia and it's important to recognise what you are responding to – are you worried about something which poses a genuine risk, or is there something else at play?

Jane also introduced the idea of emotional risk as another area of risk to consider:



Jane, a former family carer, says

**"You're looking at the physical risk for someone. But the emotional risk, and getting out there, meeting people, and seeing things, just enjoying a sunny day on the seafront or a walk through the woods. The emotional risk of someone of not having that well-being is so much more damaging in some ways."**



Remember that people living with dementia want and need to live full and interesting lives where they can do things. We all need to balance possible risk with possible reward.

This resource is on the internet. Use the camera on your phone or tablet to scan the QR code below to visit the webpage.



# Contact us

We would love to know what you think of the toolkit. We want to improve it based on your feedback.

Please get in touch with us by emailing

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If you prefer to write to us, then please address your letter to:

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[www.livingwithdementiatoolkit.org.uk](http://www.livingwithdementiatoolkit.org.uk)