

Talking Point chat room Tuesday 15 December
Q&A on Christmas and dementia with Emma from the National Dementia Helpline

HarrietD	Hi everyone - just a reminder that in about five minutes, we'll be starting our Q&A on Christmas and dementia with Emma from our helpline.
HarrietD	Welcome Emma, and thanks for joining us today :)
EmmaL	Hello Harriet, and hello everyone, thanks for having me here! I'm really glad to be involved in this chat session
EmmaL	Please feel free to ask me anything you like about Christmas and dementia, and I'll do my best to answer your queries.
beverrino	hi Harriet
HarrietD	Hi beverrino, thanks for popping in today :) Please feel free to ask a question, or you can just observe the session if you'd prefer.
HarrietD	Ok Emma, to start us off, please can you tell us a little more about your role on the helpline?
EmmaL	I'm an advisor on the evening service. The helpline is open till 8pm on Monday-Wednesdays, and I'm one of the advisors that is available at this time. We can be contacted by phone, or by email, or through the Live Online Advice service, too.
beverrino	my mum has Alzheimer's and manages to live on her own (lives by routine). I see her every day to help her - good days and bad. my dad died last november and christmas was a very difficult time for us all, but she came to our house for christmas day and she loved it. Unfortunately we didn't take any photos and the day was forgotten immediately, but she really seemed to enjoy herself. Now this year she will come again - do you think it a good idea to take photos to show her afterwards?
HarrietD	That's lovely, thanks. It's really good that there is an evening service as well as during the day.
beverrino	we did in the summer and she didn't like looking at the 'old lady' in the photos
HarrietD	Thanks, beverrino - Emma is just writing a reply and will get back to you shortly.
EmmaL	Thanks for your question beverrino - I guess it depends on whether you think she'd benefit from seeing the photos? It might be nice for you though, to remember these festive occasions in the future.

beverrino	thanks Emma, I suppose it probably depends on her frame of mind on the day as there are very mixed reactions to everything
EmmaL	That sounds like a sensible attitude. It can be so difficult to prepare things in advance - someone's dementia can be very unpredictable, as I'm sure you're aware.
HarrietD	Thanks Emma - I hope that's helpful beverrino, please feel free to continue asking anything else throughout the session :) We've also had a couple of questions come in via email, so I'll ask the first one on the members' behalf.
HarrietD	"My beloved wife passed away in August 2014. I couldn't face Christmas at home without her so I took my family to Orlando over Christmas and New Year to make some new memories. It was somewhere my wife and I used to love going to. I can't afford to do that again this Christmas - do you have any suggestions as to how we can celebrate it this year?"
EmmaL	It sounds like it might depend on the sort of Christmas you want to have? Generally though, I think we put a lot pressure on ourselves to have a 'special day', and it can sometimes make it harder to enjoy.
EmmaL	When trying to plan a celebratory day knowing that there will be an element of grief, it can be helpful to actively take really good care of ourselves, and to perhaps lower our expectations a bit. It might be unrealistic to assume that things will feel 'normal' or even particularly joyous. Perhaps just being aware that there may be points where things feel quite sad, lonely, or overwhelming, and acknowledging that this is a natural part of grieving for a loved one.
EmmaL	Having a safe, quiet space to go and reflect may help some people manage these difficult feelings. Others may prefer to have pleasant distractions on hand, be it food, activities, or family.
Cat27	My dad has vascular dementia & anything out of the ordinary disorients him & makes him aggressive. I'm torn between wanting to keep things very simple for him without spoiling things for the rest of the family. I feel as though so many people's happiness hinges on me.
EmmaL	Hello Cat27, I understand what you mean - it sounds like you feel responsible for

	everyone's Christmas, which is a huge amount of pressure to be under!
Cat27	It is!
EmmaL	We do suggest that a simple approach to Christmas can be easier for the person with dementia, but you might also want to consider having a 'quiet room' for them to go to, if it gets too much. In this way, you might be able to have a Christmas-y atmosphere with a quiet place to retreat to if necessary.
Cat27	Unfortunately I don't have the space. We've got one big open plan room with no escape & he can't manage my stairs. I guess I'll just have to take him home early if he gets too tired or stressed.
EmmaL	Might it be possible to create a kind of 'partition' using furniture? So although there isn't a separate room, there is an area of the room which is a bit more closed and might feel a bit safer - perhaps near a window so the person can sit and look out?
Cat27	Hmmmmm that's given me something to think about. Thanks Emma.
Tony	we must remember there are those suffering with dementia who will be at the Christmas & New parties in pubs etc and may act and appear to have one to many when in fact its normal for their illness
EmmaL	This is a really good point, thanks Tony. What do you think we could do to support people living with dementia out and about through the festive period?
HarrietD	Thanks Tony. As Emma said, that's a really important point. To anyone who's joined us, we've got about 10 minutes left of our Christmas and dementia Q&A, so please feel free to ask anything that's on your mind. In the meantime, here's another question that's come through on email:
HarrietD	"My dad died in February, and my mum has Alzheimer's. She is in a care home, and I take her out for tea and cake twice a week. I have my son and girlfriend living back with me, with my other son coming for Christmas. I've decided not to have mum at home for Christmas Day. I am going to go on Boxing Day and take her out, but in the meantime how do I overcome feeling guilty?"
EmmaL	It's understandable that it feels difficult to 'leave' a person on an important festive day. However it is worth bearing in mind that a person living in a care-home with the later stages of the condition might not be entirely sure what all the fuss is about on Christmas

	day. For some, the extra noise and activity may actually cause more distress.
EmmaL	Most care homes will make some effort to have a quiet celebration on Christmas day, so that the residents can have a treat if they feel like it, and so it's not as though living in a care-home prevents a celebratory atmosphere.
EmmaL	I think difficult feelings like guilt have a tendency to creep in when we compare memories of when the person was well to the reality of their living with dementia. I think these can be particularly poignant on special family occasions, and can bring about a sense of grief and loss.
Tony	well that's the difficult part because dementia suffers like myself we don't wear a sign therefor completely unidentifiable under normal conditions leave alone when are a bit merry so I assume nothing
EmmaL	Your idea to have Christmas for yourself and your family, and visit your mum on boxing day sounds sensible. I appreciate it can feel very difficult to manage everyone's expectations (including your own) and to try and give everyone the Christmas they want. It might help to be mindful of it being your Christmas too.
HarrietD	Thanks Tony - Emma is just writing a reply to you now :)
EmmaL	Thanks Tony, I'm hearing that you feel it would be difficult to tell in a busy festive environment who is jolly and tipsy, and who is living with dementia. Perhaps as a community we should all be a little bit more mindful about our assumptions.
Tony	Emma thanks it's not a problem because we can always leave but just thought i would mention people with dementia do party
EmmaL	As they should, Tony!
HarrietD	Ok everyone, I'm going to have to close today's Q&A now but thanks very much to beverrino, Cat27 and Tony for sharing your experiences and asking your questions. I hope you've all found it helpful! A massive thanks to Emma for very kindly answering everyone's questions today :) We'll also post a transcript of this Q&A along with links to extra support.
EmmaL	Thanks Harriet, and thanks to the group for having me! I've really enjoyed being involved in Talking Point today. Do give the helpline a call/ drop us an email/catch us on Live Online Advice if you'd like further

	information, some specific guidance, or some emotional support.
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Thanks for reading the transcript from our Q&A session in the chat room on 15 December.

Some helpful resources for Christmas are listed below:

General tips

- Top tips for Christmas:
https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2085&ga=1.161287549.1904842126.1399372997
- Christmas tips and advice – personal stories
https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2802&ga=1.210634965.1904842126.1399372997
- Tips for supporting someone with dementia, both inside and outside the home:
https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2463&ga=1.210634965.1904842126.1399372997
- Useful winter guide from Independent Age:
http://www.independentage.org/media/1136264/being_winter_wise.pdf

Factsheets

- Eating and drinking factsheet:
https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=149&ga=1.168773985.1904842126.1399372997
- Safety in the home factsheet:
https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=145&ga=1.168773985.1904842126.1399372997
- Understanding and supporting a person with dementia factsheet:
https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=84&ga=1.174345314.1904842126.1399372997
- Travelling and going on holiday factsheet:
https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=158

Gift ideas

- Winslow Resources:
<http://www.winslowresources.com/>
- Alzheimer's online shop:
<http://shop.alzheimers.org.uk/>

Other organisations

- Samaritans:
<http://www.samaritans.org/how-we-can-help-you/contact-us>
- Age UK:
<http://www.ageuk.org.uk/contact-us/>
- Dementia UK:

- <https://www.dementiauk.org/contact-us/>
- Admiral Nursing Direct:
<https://www.dementiauk.org/how-we-help/admiral-nursing-direct/>
- Mind:
<http://www.mind.org.uk/about-us/contact-us/>

Alzheimer's Society National Dementia Helpline

Our helpline - 0300 222 1122 - can provide emotional support, as well as guidance and signposting to other appropriate organisations. The helpline is usually open from 9am to 8pm Monday to Wednesday, 9am to 5pm Thursday to Friday and 10am to 4pm on Saturday and Sunday.

Christmas and New Year opening times

On Christmas Eve and New Year's Eve, the line is open 9am-1pm. It is closed from Christmas Day until Monday 28 December, and on New Year's Day.

You can also email the helpline team at helpline@alzheimers.org.uk.

If you have questions about our chat room, please contact us by emailing talkingpoint@alzheimers.org.uk.

You can view the chat room here: <http://forum.alzheimers.org.uk/chatroom.php>