Dementia Case Studies

Responses to Changes and/or Challenges

NOTE: Every individual situation needs to be considered separately, in the light of all relevant circumstances. These case studies simply give an indication of how to approach things sensibly, making reasonable adjustments and, as appropriate, working with your Parish Safeguarding Officer, within our parish/Diocesan/national safeguarding framework.

Jaden and Zoe

Jaden and Zoe live near to St Peter's Church. Jaden was diagnosed with dementia two or three years back – and you believe he is living with fronto-temporal dementia. For the last year or so, he's been coming to a church coffee morning regularly, which you coordinate. His partner Zoe drops him off at church, so that she has an hour to get on with the weekly shopping, before coming back to pick Jaden up – and it gives Jaden a bit of a break too. Last week, he got agitated and wanted to leave and walk home: he took a bit of persuading to settle down and have a cuppa. Also, you've been noticing Jaden becoming more tactile over the months; today when you welcomed him he wanted to give you a kiss. He's never done that before and you are left wondering about boundaries and safeguarding.

- Assuming that Jaden has capacity, the appropriate next step is to involve Zoe and Jaden. Explain that you want to make sure that everything is in place to continue welcoming Jaden to church and ask for their consent to talking to someone else.
- If there's a risk and consent is not forthcoming, it is still appropriate to disclose the situation to the Parish Safeguarding Officer, anyway.
- The coffee morning leader, the Parish Safeguarding Officer and Jaden and Zoe can together focus on what's happening and what helps, to manage things sensibly. This risk assessment becomes a plan, setting out sensible action to reduce risk, going forwards. This can then be shared appropriately with others involved in running the group, so that everyone is working to the same sensible, safe practices.

Lily

Lily has been coming to church for years – and you think she's had a diagnosis of dementia but you're not sure which type. She never used to swear, but you are noticing some swear words slipping into your conversation with her and you're worried that other people may be offended. You heard some loud "tutting" from others at church today, over this.

- Reasonable adjustment here would simply involve making people who are offended aware that Lily is not intending offence but can't help it on occasion.
- This needs to be done imparting minimal information as to the circumstances: limited information can be provided to others on a "need to know basis" where a risk impacts on others.

Mikael and Anya

Mikael and Anya are regular members of the congregation at Holy Trinity Church. Mikael was diagnosed with vascular dementia and some years back and patterns have been changing for them, as a couple, over time. Anya is Mikael's main informal carer: Mikael isn't driving any more and he's needing more support from Anya for everyday living. Also, this year there has been a

marked change his mood and behaviour, becoming more volatile. Mikael is getting increasingly frustrated - and today after a church event you heard a real verbal outburst, with him shouting at Anya and hitting out at her. It's left you concerned for her personal safety, but you know that things are at full stretch for them and you don't want to put extra pressure on them.

- What should you do immediately? Speak to Anya, expressing your concern for her safety. Say that you're aware it's important to talk to the Parish Safeguarding Officer – and you wonder where there's a key worker who can helpfully be involved, too.
- When will there be a statutory key worker, a social worker, in place? A referral is made when there is a carer's assessment or when a care package is in place; it can also be made after someone has been in hospital. So it will be important to work with the key worker, if one is in place. If a key worker is not already in place, we can make referrals to social care too.
- The discussion, involving Anya, Mikael, the Parish Safeguarding Coordinator and key worker will focus on what triggers frustration/violence/hitting out, noticing patterns e.g. particular times of day. They will summarise the risks, the triggers and what works to placate that behaviour.
- This can then be shared, as a basis for responding appropriately and supporting Mikael and Anya. Information for the protection of an individual, or the protection of others from that individual, can be shared on a "need to know basis". In other words, it can be shared with people at risk from that behaviour or others with a role in that person's care.
- What if the behaviour changes, as the dementia progresses? Any plan should be reviewed and it's helpful to agree the frequency of review at the time you when the plan is made; if required, an unscheduled review can be held.

Andrea

Andrea is retired, but in her working life she was a company director shouldering significant management responsibility. She's a respected member of the community and a core member of the local church. In the past, she has been a member of the General Synod of the Church of England and has also been a churchwarden, but she has retired from both these posts. Andrea was diagnosed with dementia three years ago. She is still a School Governor and values this role, although she acknowledges that she is finding it increasingly difficult to keep up with the paperwork involved.

- It sounds as though it is the right stage for Andrea to step down from the "business" responsibilities of a School Governor, now that it is difficult to keep up with the paperwork.
- It may be appropriate to explore the possibility of Andrea remaining in place as an "Associate Governor", so that she continues to play her part in the way she values, without having to be involved in the business side. It is good to notice what she can do appropriately and values doing – perhaps saying an opening prayer, to start the meeting.

Joe

Joe comes to the church service at Christchurch most Sundays. He's lived with dementia for some years and lives alone. He's started to use his phone during the service, sometimes with sounds, in a way that's distracting to other people.

- Here, the tipping point is where Joe's behaviour interferes with the service.
- If he is on the phone but not disturbing others, then no challenge is required. If the sound is on, it may be appropriate to ask him to turn off the sound.
- Given cognition issues, it may be necessary to ask Joe to turn off the sound every time he comes to church, as it would not be reasonable to expect him to retain the information and permanently his modify behavior.

Kim

Kim is a Lay Reader and a member of the choir at St George's Church. She's been living with dementia for a while. She loves singing and joining the procession in church. But her balance isn't as good as it used to be and it's becoming more of a challenge to process in and out of church – and it's also a bit more challenging to find the right music for the next anthem and hymn during the service.

- It's important to be able to support Kim, as patterns change for her.
- It may be appropriate for her to sit in the choir stalls, rather than processing in and out, giving that balance and mobility are becoming more of an issue.
- It may be appropriate for a fellow member of the choir to offer support, sensitively, in helping to turn to the music for the next anthem or hymn. Or it may help Kim to add tabs as markers.
- It's important to remember that dementia is a progressive disease – and so we can expect that patterns will need to change, over time. It's no-one's "fault" if you are needing to move on from a pattern which used to work well, but no longer fits current needs.
- It's good to notice what's life-giving for Kim – and what fits with the shape of worship for everyone. For example, it may be reasonable to continue to support a choir member with advancing dementia in leading the choir prayer at the end of worship: this continuing participation might be meaningful for the individual concerned and for others in the choir too.

Mary

Mary comes to a singing group at church. People running the group have recently learned that she's got a diagnosis of dementia. They are thinking that they should say that she needs to come to the group with a carer.

- Don't assume "one size fits all". If a person living with dementia is "required" to bring along a carer in these circumstances, simply because of

their diagnosis, that may be unduly restrictive. It can feel pigeon-holed, simply to "require" someone with dementia to come with a carer because it doesn't take account of the person's specific circumstances. There are early stages of dementia, as well as middle/late stages.

- For example, at a particular stage for someone with a diagnosis of dementia, it may be that, on a good day, the person is still able to drive to the group "solo" and participate steadily; on a less good day, it might be appropriate for their partner to come too; and on a bad day the couple might reasonably decide that they won't come at all. Also, dementia is a progressive disease, so patterns that work for a season may need to adapt, as the dementia progresses.
- A helpful approach might be to have a welcome form for everyone, which includes contact details of next of kin. It may be helpful to keep in touch with Mary and her partner / family / next of kin about how things are going. This could involve discussing how things are working at present and recognising that, since dementia is a progressive disease, you will be in touch if you get to a point where Mary's needs are beyond what can be supported by volunteers at the group, so that she would need to come with a carer.
- Be clear about what you can and can't offer at the group. For example, if someone gets to the point of needing personal care to go the toilet, you will not be able to support this (unless your group is set up for this, with appropriate training / processes in place e.g. DBS Checks).

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October 2024