



Dementia in our Quaker meetings



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Introduction

Dementia is an issue faced by many Friends. They might experience it directly or when caring for or loving someone with the condition.

In this leaflet we offer some thoughts on being together in a Quaker community when dementia is present. The reflections here might be helpful for someone living with dementia, for those supporting someone with the condition, or indeed for anyone in the wider Quaker community.

We have drawn on contributions offered at the Quaker Mental Health Forum – ‘Dementia: our shared journey’ – in December 2017, and include some passages shared on that day. We end with some queries that might be helpful for reflection.

As our starting point we share these words of George Fox:

“Friends, meet together and know one another in that which is eternal, which was before the world was.”

From Epistle 149, 1657
Quaker faith & practice 2.35



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How do we meet together as Friends?

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Meeting together can bring joy and strength

“Paring our relationship down to the essential of being together, without expectation or judgement, was surprisingly liberating. There was much joy in simply being together.”

“The sense of being loved, respected, cared for, upheld, is always with me.”

“I will never know what was going through his mind, but I held on to the thought that deep within him there was something more than his thoughts, feelings and physical body; there is our essence which survives, a feeling of love which would comfort him.”

It can also be difficult

“When we cannot ‘know one another’ as we expect, all can become puzzled and disturbed. If people do not respond as we ‘expect’, this can cause anxiety, uncertainty and possibly avoidance, because we cannot make sense of the situation and are not sure what to do.”

Jane Muers, adapted from the Retreat Lecture 2014

“Most Friends who had known her ... gradually stopped visiting her. Her decline shocked them, touched a raw nerve: perhaps they did not know how to relate to her anymore.”

“Family and friends can melt away for lots of different reasons, just as we withdraw from them.”

How do we meet together as Friends?

It can be painful

“...I found an older Friend in tears. ‘I hate this dementia,’ she cried, ‘I hate what it is doing to Anne.’ She was distraught to hear Anne describing how lost she felt that morning...”

‘Meet’ through attending to feelings and needs rather than to information and reasoning

Whether we encounter dementia directly or indirectly, the experience can change us.

“I hold in my heart the memory of getting very confused, and someone, recognising my distress, took both my hands and said: ‘I know you are frightened, but you are here where you are supposed to be. You are safe and we love you.’”

“It is easy to feel inadequate and low, so a positive upbeat Quaker response that focuses on practical solutions without hearing the emotions can make the carer feel even more inadequate.”



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How do we meet together as Friends?

‘Meet’ the individual, trying to understand their experience

“I would always start from where they were, accepting the emotions, being quiet and calm in my heart – holding them in the light. It was all about hearing their story...”

‘Meet’ in spirit in the present moment

“When I feel inadequate and lost myself, I remain in the present moment no matter how fragile it feels. I feel that is a gift we can give and at those times we may feel the sacredness and preciousness of that moment.”

“The journey of dementia is a spiritual journey.”

“Looking back, I know it was a relationship of equals. It wasn’t about me caring for a friend who was a victim of illness and diminished by it... Our friendship was strengthened as we continued to accompany one another in the spirit. That is a precious gift.”

Some reflections on issues raised by dementia

Quaker worship

At its best, Quaker worship does not need words, or thoughts – but openness and love. If you are living directly with dementia, Quaker worship may be ideal for you. The silence may be healing and calming for you; you can be a valuable presence there.

Some people living with dementia may be anxious and worried and may struggle with silence. Some people may forget the conventions of worship – when to speak, how long to speak for.

If worship is difficult for a Friend in your meeting, consider whether someone can agree to sit with them to support them and help them to feel safe. Maybe a shorter meeting for worship could be arranged, or worship in the Friend's home?

No longer able to serve?

Everyone will at some point need to be released from roles we hold within our meeting. It may be hard – or it may be a relief.

Sometimes a meeting may be worried that a Friend is no longer able to perform their duties. Can the Friend be supported in some way to continue?



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Some reflections on issues raised by dementia

If you are living with dementia, some roles may not be sensible for you to attempt – but there are probably other things that you could manage and which you might now do better.

Honest discussion will always help. Some people want to be busy and to feel useful and some find this a burden.

For all of us, it is our presence that is our essential gift to the meeting.

Being alongside

Everyone's experience of dementia is different. Most will have feelings of grief, loss, anger, fear and distress at times. It can be hard for family, friends and for a Quaker meeting to see how dementia changes someone they love. A loving community will find ways to reassure, to empower, to hear, to hold, to care for and to be cared for by a friend who has dementia. Meetings are not support groups and should not try to fix things – but they can be a source of comfort and solace.

Difficult behaviour

If you have dementia you may not remember the conventions of how we conduct ourselves in a Quaker meeting. Some people with dementia lose some of their inhibitions and may say whatever comes to mind, may use language they would not previously have used, or do whatever they feel like doing. If you are living with dementia you are likely to have times of great frustration and despair; some people may sometimes express this through aggressive words or behaviour.

Some reflections on issues raised by dementia

Always consider the person who is living with dementia: “When words are strange or disturbing to you, try to sense where they come from...” (*Advices & queries 17*)

It may be helpful to remind the person who has dementia of how things usually happen – and they may need frequent reminders. It may be helpful to find some way of hearing their concern – a separate discussion outside meeting for worship, for instance. Sometimes it is not possible to accommodate the needs of someone who has dementia within the meeting; we can encourage each other to be honest and open together.

Dementia is a potentially serious long-term condition

If you are living with dementia you may need support to acknowledge your situation, to make plans, to say what you need to say – just like anyone else who lives with a life-changing, long-term condition. You may need support to make sure you make plans while you are able to do so.

“As far as possible, make arrangements for your care in good time...”

Advices & queries 29



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Supporting the supporters

If someone you love has dementia you will be experiencing a web of emotions. If you are involved in their care you may be facing the difficulties of accessing services and dealing with bureaucracy. If you are physically caring for someone who has dementia, you are undertaking a task that can be difficult and isolating – but that can be rewarding. Someone who is living directly with dementia will have a network of family and connections; these may be hugely supportive, but can also be stressful.

Everyone who is caring needs help and support. Some people simply ask that we hold them in the light; others welcome practical help; some people need space to talk.

It can be hard to know what to do and hard not to try to offer solutions. Take courage – a simple “What do you need?” can be valuable. It may be hard to respond: it’s important to be honest about our limits.

It is important that a Quaker community knows and acknowledges what people are doing and does not forget the people who don’t come to meeting because they’re busy caring.

Some queries to aid reflection

- 1 How can we encounter dementia with honesty and love?
- 2 Do people's views of dementia block out the individual and their family?
- 3 Do we listen carefully and respond to an individual, their experience, feelings and needs, or do we impose our own solutions? When suggesting solutions, do we think it possible that we may be mistaken?
- 4 When our 'solutions' do not meet the needs, does our endurance dwindle and we drift away?
- 5 How can we provide emotional support without conditions, through love?
- 6 How can we reach out to those providing support and support them?
- 7 Can the environment of the meeting house be adapted (e.g. signage) to make it more accessible to Friends with dementia?
- 8 How can we all learn more about dementia and its effects?
- 9 How can we use our experiences of dementia to explore our spiritual journeys, and to consider questions of forgiveness and acceptance?
- 10 How can we look at things differently?



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Some queries to aid reflection

Dementia is not a new concern

The old age of William Penn

“His memory was almost quite lost, and the use of his understanding suspended; so that he was not so conversible as formerly; and yet as near the Truth, in the love of it, as before... His mind was in an innocent state, as appeared by his very loving deportment to all that came near him: and that he still had a good sense of Truth was plain, by some very clear sentences he spoke in the Life and Power of Truth ... wherein we were greatly comforted...”

Thomas Story, 1714
Quaker faith & practice 21.62

Contacts and Resources

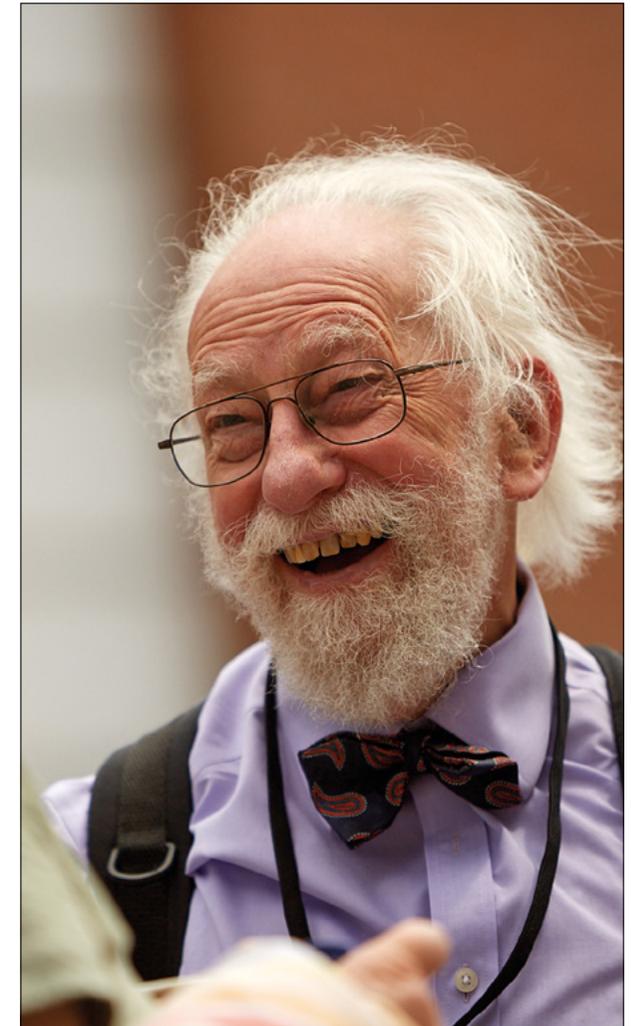
Quaker Contacts

Support for meetings supportmeetings@quaker.org.uk

Resources

You may find the following organisations, websites and contacts useful.

National Dementia Helpline	0300 222 11 22
Alzheimer's Society	www.alzheimers.org.uk
Dementia Friends	www.dementiafriends.org.uk
Dementia UK	www.dementiauk.org
Live Better With Dementia	https://dementia.livebetterwith.com
Age UK	www.ageuk.org.uk/dementia
Carers Trust	www.carers.org
Carers UK	www.carersuk.org



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