Living, Dying and Remembering

Supporting People with Learning Disabilities

Ian Leech, Project Lead, formerly of St Giles Hospice
Alison Wellon, Friends 2 Friends Chief Executive
James Channon, Friends 2 Friends Member
Simon Cox, Friends 2 Friends Member

The Learning Disability Project

- The Hospice was awarded a grant by the Masonic Charitable Foundation (MCF)
- The aim was to widen access to hospice care for people with learning disabilities and create a network throughout our catchment area
- Choose your partners wisely!
- Our Steering Group.
- The Impact of Covid
- The Impact of our Steering Group

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A Series of Tasks

We set out a series of tasks that we wanted to achieve, these included:

- Embedding the project in the hospice
- Build a network of local groups and organisations and develop their understanding
- Introduce a system for monitoring access of our services by people with LD
- Develop a network of 10 trained Learning Disability Champions
- Develop and build links with 12 local groups/organisations
- Provide End of Life and Bereavement Training for 50 staff from the local Learning Disability Community. This was done over three sessions.

- The Survey

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The Thoughts of Friends 2 Friends

As an organisation, why did you want to take part in this project and why is it important?

Questions for James and Simon:

What did you think when you were first asked to join the project?

Has it changed the way you think and talk about death, dying and bereavement?

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They are the Champions

- Communicate in a way that the person can understand
- Appreciate the barriers people with learning disabilities experience accessing palliative and end of life care
- Help to reduce the barriers for people with learning disabilities accessing palliative/end of life care and bereavement support by making reasonable adjustments
- Feel comfortable discussing Advance Care Planning and the challenges of End of Life Care communication and conversations
- Signpost people with learning disabilities to relevant support services if necessary
- Support, and work alongside people with learning disabilities by improving palliative/end of life care and bereavement

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" Working together, listening, learning and sharing to make things better"

Simon and James 2021

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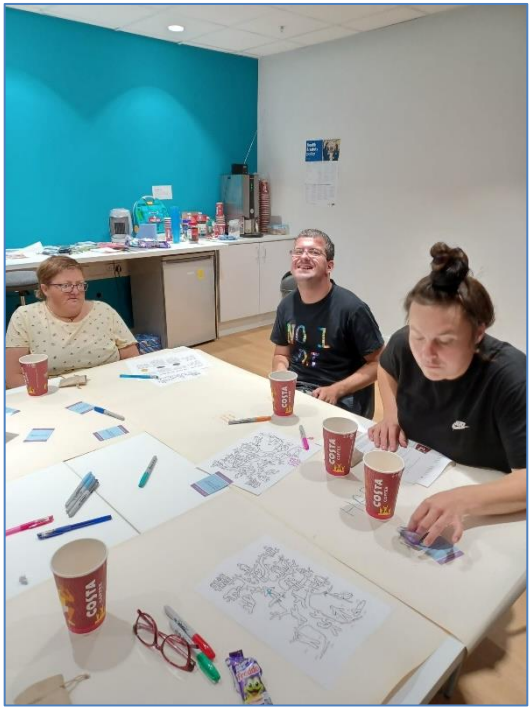
Talking Grief with Friends 2 Friends

A series of workshops exploring how we can encourage Friends 2 Friends members to talk more opening about their grief and loss:

Key Themes were:

- Exploring emotions
- Talking about Memories
- Looking after yourself



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Looking to the Future

- To continue the develop of the network of Champions and agree future aims and objectives
- To improve Palliative and End of Life Care resources for clinicians and partners, who are caring for patients with Learning Disabilities
- Identify further funding opportunities for initiatives and projects that address the inequalities of care for adults with Learning Disabilities

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Thank you

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