Younger people with dementia
Resource Development 2012 - 14

Iain Houston – Alzheimer Scotland
Context and background

- Around 90,000 people with dementia in Scotland
- Estimated number with younger onset dementia 3,200
- Consultation between Glasgow Younger Persons Support Service (GYPSS) and younger people with dementia and their families
- Comments on lack of age appropriate information
- Few images of dementia representing younger age group
- No funds to committed to producing resource
Initial development

- Alzheimer Scotland obtained funding from NHS Health Scotland
- Strong commitment to partnership working
- Alex Murphy (Service Manager) Glasgow Younger Persons Support Service
- Fiona Borrowman (Health Improvement Manager) NHS Health Scotland
Part of a series of information resources for people with dementia and families and carers
The Process – how we developed the resource

Involving people with diagnosis of younger onset dementia and family carers was key:

– Workshops

– Filming stories

– Pre-testing film footage & text

– Extra filming following pre test with target audience

– Pretested text & design with SDWG
Workshop July 2012 to inform process - feedback

- Is the resource needed?
  - ‘Agreed need for resource – huge gap’
  - ‘Resource will raise awareness of Younger Onset Dementia with range of professionals’
  - ‘Need to film real people and stories’

- What would have helped and what did help?
  - ‘Support after diagnosis’
  - ‘Telling positive stories’
Workshop July 2012 to inform process - feedback

**Practical information**
‘Communicating with children and young people about the diagnosis’
‘Coping strategies’
‘Information on work, finance, driving, benefits’
Peer support & networks
Help for isolation for carers
‘Staying involved with community’
‘ Person centred’

**Planning for the future**
Legal advice
Access to benefits advice
Difficult conversations need support
Some comments about resource development at pre-test:

- “DVD as a good way to tell the story“
- “This is just like my story ”
- “Publication looks and reads well – like the colour coded chapters”
- “Coloured speech bubbles are ‘friendly’ and easy to read – break up the page when vision is difficult”
- “Good to have photos”
- “Help card is really helpful”
Questions/Feedback required

Aim was for a resource that will be:

- Informative
- Supportive
- Helpful at time of diagnosis for person with dementia and family
New Younger people with dementia resource

- Printed publication including DVD
- DVD with PDF of publication
- Online versions of publication and DVD available
What happened next?

- Launch at Younger Adults with dementia conference Nov 2013

- Demand from professionals - third reprint

- Commended BMA Patient Information Awards

- Feedback from other parts of UK, Australia & Taiwan very positive

- Twitter from Australia from people with diagnosis ‘Well done Scotland’!
Thank You!

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