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Post Diagnosis Support in Early Stages of Dementia

Reinhard Guss, Sue Watts, Prof Esme Moniz-Cook

Alzheimer's
Society

Leading the
fight against
dementia

deep

The Dementia Engagement
and Empowerment Project



Good post-diagnostic support

- Needs to be timely and sensitively paced
- Includes working at different levels:
 - providing opportunities for rehabilitation and adjustment,
 - through psychotherapy or peer support groups, choices of support options
 - working with the person with dementia/their carer/system
- ‘Stepped’ system of care to match needs



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Good post-diagnostic support

- Needs to :
 - Be timely and sensitively paced
 - work at different levels of complexity and skills
 - provide opportunities for rehabilitation and adjustment
 - Offer from psychotherapy to peer support groups, choices of support options
 - work with the person with dementia, their family carer and systems
- ‘Stepped’ system of care to match needs
- Involve range of disciplines, professions and levels of training



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Evidence base for interventions with people affected by dementia

Type of Intervention	Selected references
MCI interventions	Tuokko & Hultsch, 2006; Cantegreil-Kallen et al., 2009
Adjustment to the illness (e.g. through support groups)	Cheston and Jones, 2009; Sorensen et al., 2008; Logsdon et al., 2010; Sadek et al., 2011
Education about dementia symptoms and coping strategies	Moniz-Cook et al, 2006; 2008
Psychological therapies for depression and anxiety (e.g. CBT)	Lipinska, 2009; Miller and Reynolds, 2006
Life Story and Reminiscence	Young, Howard and Keetch, 2013; Cochrane Collaboration Review: Woods et al, 2009
Dementia Cafés	Jones, 2010
Cognitive Stimulation Therapy	Cochrane Collaboration Review: Woods et al., 2012; Orrell et al., 2012

Evidence base for interventions with families of people affected by dementia

Type of Intervention	Selected references
Cognitive rehabilitation in early dementia and help to maintain activities of daily living/lifestyle	Clare et al., 2010; Kurz et al., 2011 ; Graff et al., 2006; 2008
Group and individual adjustment work with carers	Cochrane Collaboration Review: Vernooij Dassen et al., 2011; Charlesworth et al., 2009
Coping strategies and stress management for carers	Cooper et al., 2012
Understanding ‘challenging behaviours’	Selwood et al., 2007



Summary

- ❑ Concerns over lack of provision, and uncertainty over who should provide this
- ❑ Evidence for efficacy of post-diagnostic interventions for both people affected by dementia and their families
- ❑ Persuasive arguments for stepped care model of provision
- ❑ A post-diagnostic psycho-social intervention gap - diagnosis without adequate support is often not beneficial, and can be detrimental
- ❑ Need to include specialist psychological therapies and neuropsychologically informed treatments as part of post-diagnostic care.



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A Guide to psychosocial interventions in the early stages of dementia

- An overview of psychological and psychologically informed treatments and support for people with a new diagnosis of dementia and their families
- In alphabetical order, brief description, what might be gained, who is qualified to provide, where to find further information, where might be offered, summary of evidence base, key references
- Accessible language and structure
- Needs based index grouping interventions addressing similar needs, e.g. dealing with anxiety/depression or maintaining cognitive functioning
- Successfully trialled with people with early stages of dementia



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Views from People with Dementia:

Nada Savich; Keith Oliver; Kent Forget-Me-Nots; DEEP; Rachael Litherland; Reinhard Guss; James Middleton, Lewis Slade, EDUCATE Stockport, Friends together Redditch, Scottish Dementia Working Group

Compendium of Psychosocial Interventions:

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