Limited receipt of support services among people with mild-to-moderate dementia: findings from the IDEAL cohort

Do people affected by dementia have access to post-diagnostic support?

People with dementia need information and services to help them live well. There are national recommendations about the support that should be available. Everybody should receive this support, but we wanted to find out if everybody did.

We asked hundreds of people with dementia and carers:

- is there a named professional you can contact?
- have you been given information about dementia?
- have you been to any support groups?
- have you asked for information about dementia?

About half the people we asked said they had received support. Age, gender and education level made a difference to how much support they received. We found that older women with lower levels of education got less support than others.

The relationship between the person with dementia and the carer also made a difference. If they were married or partners, they received less support than if they were family members.

People with some types of dementia got more support than others. People with Parkinson’s disease dementia or dementia with Lewy bodies received
more support than people with Alzheimer’s disease.

We don’t yet know why these differences exist:

- support could be unavailable, or inaccessible
- people might not know about existing support services
- people might not look for support

It’s important that everybody with dementia has enough help. Our findings show that not everyone receives equal support. Understanding why can help improve services for everyone.

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