"How do the patients and their close relatives experience The Coordinated Investigation Model of Dementia in the North Denmark Region?"
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Dilemmas

It’s not easy – A dilemma is a problem, offering two possibilities, neither of which is practically acceptable.

Main results

The Coordinated Investigation Model of Dementia in the North Denmark Region

Citations

Further information about the project

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"Surely, what we really want is some kind of treatment (for speech problems). That’s the most important thing. Our daily life works well – no problem” (the patient with dementia has lost the ability to express herself sufficiently, and her spouse wants help to regain her verbal skills).

"To remind my father to feed the horses … I’m not sure that the municipal nurses are allowed to do that.”

"I wish we had snow all year round, so my husband had something useful to do. It is so important for him, because he has cleared the pavement for snow, he has done a proper piece of work.”

"We got a leaflet about a meeting about dementia; we were invited by a meeting in Aalborg with other people who would talk about their experiences. But I didn’t go there … I have a sister-in-law, on the same thing happened to her… (She suffered from dementia) I don’t want to learn more … it’s no good looking ahead for trouble.”

"We don’t need any help, we want to take care of ourselves. She can still cook, she can bend down to the ground and remove weeds in the garden … I can’t (spouse with grave physical handicap)."

"To have tea and just a few hours, to take a short trip to town, that’s all right. As long as he doesn’t run away from home, he hasn’t done it yet. And luckily, he sleeps during the nights.”

"The relatives experience that the social medical help is optimized when relevant help is offered at the right time and the patients and their relatives experience that their needs are fulfilled.

"But the help, that is wanted, can’t always be offered or might not be considered relevant.

"A common understanding in families with a person suffering from dementia and clarity about plans for the future is necessary in order to make a satisfactory follow-up.”

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"The purpose of The Coordinated Investigation Model is to involve the patients and their relatives in the investigation, the information and the decisions made by specialists in the secondary sector.

"Some of the relatives want and need to be informed about dementia.

"But patients with dementia often can’t manage to get involved and participate on equal terms in the process.

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"In safe hands” – knowing that the dementia nurse is available and responsive makes the patients and their relatives feel safe.

"Patients desire for autonomy, combined with lack of realization of their disease often put their relatives in dilemma and cause transboundary situations.

"The role of the dementia nurse as main coordinator of the investigation process is generally appreciated by patients and their relatives, because she is proactive, easily available, helpful and takes her time.

"The relatives are not sufficiently involved in the investigation process, carried out by the general practitioner and dementia nurse.

"The patients and their relatives want to take care of themselves and ask for support to "feel safe” and relevant support at the right time.

"Trust and confidence in the doctor and the nurse is more important than information for some patients and their relatives.

"But patients with dementia often can’t manage to get involved and participate on equal terms in the process.

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