

Implementing a Dementia Positive Living Group

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Background

The need for Hospices to be involved in Dementia Care was emphasised by the publication of Hospice Enabled Dementia Care (2015) by Hospice UK and Hope for Home.

The local CCG met to discuss Developing a Dementia Pathway for East and West Suffolk, and the main gap seemed to be following diagnosis. Unlike other conditions, people do not seem to have a key person to go to for help and they are not made aware of the support that is available. At St Nicholas Hospice Care we started to look at the ways that we could offer specialist palliative support for those coping with dementia and used feedback from both staff and previous service users who were coping with dementia who had accessed various parts of our service. It was felt the best way forward would be to work jointly with the local dementia trainer and a nurse from the Memory Assessment Team at the West Suffolk Hospital (REF H UK-see end) and adapt our Positive Living Group (see separate sheet)

Aim

To provide people with the information to plan for their future – including discussion about advanced care planning, in which the Hospice specialises – but also working with other professionals to give information and signpost to allow choices for future support.

Method

Referrals taken from any clinician or attendees can self refer.

Maximum of 7 couples per course.

The Group is held off site – away from the Hospice in a nice setting. Lunch is provided to allow the chance for informal chat and results in the Group getting to know each other informally, which has the effect of more open discussion, promoting conversation and peer support.

The four weeks course in a closed group setting comprising of

- Week 1 – What is Dementia, what is going on for us?
- Week 2 – The Art of Communicating and Living with Dementia
- Week 3 – Planning for the Future
- Week 4 – What Support is Available – we have someone visit from the Dementia Cluster of Social Services and from Sue Ryder who currently hold the contract for delivering dementia services in Suffolk

At the end of the course, unless clinical need dictates, we discharge the attendees from Hospice services, they have written information on course content and essential contacts.

Results

We have received 17 referrals, since March 2017, for 2 courses (14 spaces), one in April, and one in September. Minimal advertising / marketing has been done

Referrals were received from the Memory Assessment Clinic, GPs, self referral, social services, and hospice.

All the couples completed all the sessions.

The first course was featured in the national Alzheimer's society magazine "Living with Dementia". As far as they were aware, we were the only Hospice in the country running this sort of service.

All feedback, from attendees, has been positive.

Most feedback emphasised the benefit of a small group.

"We have been given confidence; now know where to go to for appropriate help."

"Most helpful to find out what would happen if I fall ill or go into hospital with regard to what would happen to my husband."

"We gained friendship, not feeling on our own and that people do care."

"Meetings have been full of information and laughter which is a great tonic to us all."

"My husband has been more animated – laughing and joining in – than I have seen him for a long time."

"It has provided me with a lot of essential information, making me more confident to face the future."

"I have attended a number of other groups, but, due to the (organisation) the exchange is more open in this group."

The first group continue to meet, at least, monthly – maintaining the peer support that they developed on our course.

Conclusion

This has been a positive experience for those involved, highlighting the need for a collaborative approach with local services and the significant contribution St Nicholas Hospice can make supporting people with dementia

Our courses remain oversubscribed, we will run the third one in the pilot and then look at getting funding to be able to run at least 3 a year in the future.

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