

Hope for Home-Terminal care of Advanced Dementia



Before.....and after discharge home from nursing care

Case examples

Grace, in her 70s, developed a multi-infarct dementia. She became very agitated distressed and went into a nursing home. Within two weeks she had lost weight, was bruised, distressed and ended up sitting on a dementia assessment ward. She called out repeatedly numbers from 97 to 100.

Sitting in a basket chair it was difficult to see what could be done to alleviate her distress or to care for her. Judicious use of anti-psychotics and antidepressants had some benefit and benzodiazepines were used as well. She didn't do that well but settled enough to go into a dementia specialist nursing home. There she lost weight, continued to be distressed and her husband could not bear to see her in such a way. He asked if he could take her home. The nurses and consultant all said they were very worried about this and thought it a bad idea. Her husband insisted and after discussion it was agreed that this could be tried. Wonderfully, Grace did well. In fact she lived at home for eight years. She gained weight and was happy in the care of her husband along with a small but loyal group of carers who supported her husband. For a lady who was fully dependent, needed full nursing care including feeding, it was extraordinary to see her on trips out to shopping centres and her beloved golf club etc. Grace's long survival was, I think, attributable to the combination of good care with the fact that this was a Multi-infarct dementia and not an Alzheimer's type dementia. Her dementia stabilised for quite some time and did not progress, explaining the unusually long length of time at home.

Others with dementia have had similar experiences, keeping their loved ones at home for between a couple of months and two to three years. Some went home from nursing homes. Overall, we have looked after 15 or so patients with such needs at home over the last five years in Bexley and Greenwich. With no dedicated funding and no formal service we are currently caring for eight such people in their homes.



At home on Christmas day, a fortnight before Grandma died

One lady, surrounded by family in prayer had not responded for 48 hours to anything. She made a sign of the cross: the last sign of responsiveness she made in her life. She died peacefully that night. It felt almost inconceivable that the opportunity of family presence in such a way could have been achieved elsewhere.

Introduction

Very many people hope the aspiration that when they die, they will die at home in the care of their loved ones. Of course this reality does not turn out for very many people. In cancer care large efforts have been made to develop community team's who will provide palliative care and advice on all aspects that patients need to stay at



home. This work has been successful and well received by local communities and funded by charitable money.

By contrast the vast majority of people with dementia die in hospital or residential/ nursing care. Few people with advanced and complex dementia die at home and few live at home in the months or years leading up to the end of their life. In part this may be because the demands of

advanced dementia are not the same as the demands of cancer care. Increased levels of agitation, depression, psychoses and behaviour disturbance are all common features of severe dementia. But, the fact that people with severe dementia have poor mental capacity and poor understanding is an additional cause of complexity. Often enough, palliative care in other situations sees palliative care implemented at a time when the patient is mentally competent and able to understand and work with the things that are being proposed and done for them.

Despite these problems, it is now clear that care for advanced dementia at home is feasible. Experience in South East London has shown that regular input at home with specialist medical and nursing advice and support has enabled people with advanced dementia, requiring 24-hour nursing and physical care, to be provided for at home up until the time of their death. Early results from qualitative research have shown that things were better as a result of care at home and that the success of such care requires a broad range of categories of support to make it successful.

Intrinsic carer factors

We think that it is necessary for carers to be relatively robust, determined to succeed and in reasonable physical and mental health. Mental frailty in the key carer seems to be particularly problematic. The key carer will often be a spouse, but at other times may be a daughter or son or a friend etc. We have found that carers face obstructions in the work they do and at times have had to negotiate robustly with care managers, doctors, nurses and others. Many carers have had to purchase equipment which they found they could not get soon enough from statutory services. While in one sense at least this is quite unacceptable, it does seem to reflect the reality that this style of care is not well facilitated by statutory services. Each carer, however robust requires the support of others.



Appliances

A wide range of appliances are needed. Hospital beds which can be raised and lowered and adjusted are almost universally needed. Cushions which will raise pillows effectively are important and often not provided. Zimmer frames, commodes, bath seats, wheelchairs showers (or better wet rooms) and many other bits of equipment should be available when needed. Proper pressure relieving cushions for chairs are also needed.





Later on hoists are required. Standing hoists (when the patient is suspended from a single point) are obtainable from primary care trusts but many of our patients have also needed sitting hoists. So at times when hoists are needed for care at home they need to be available on time: if the carer can no longer lift their loved one, they will end up in care as a result. Carpet cleaners help too!

Space and people power

Some patients have been cared for in large Victorian homes with large families and lots of people. Others have been cared for in one bedroom maisonettes and small cottages. It is therefore possible to provide this style of care in a wide range of settings. An important principle is the willingness to alter the furniture of any setting. Space must be made to meet the primary need of bed, space for personal care, hoists and all the other bits of equipment required. Space for people to sit around a bed is also very useful. Sometimes the happiest moments for patients appear to be when two to three people are gathered around a bed where the patient can rest and where conversation about ordinary and normal things can continue.



Obstructions

Reluctant care managers, funding disputes, uncertainty about whether a person resides in the district where they own their home or with the family with whom they are staying, and many other factors have led to apparent obstruction to the provision of care at home. Often enough it may be that care managers, doctors and nurses are fearful that patients will come to harm as a result of being cared for at home. And yet dementia is a terminal illness: surely in such a circumstance it is right to take some risks to put in place a care structure that persons closest believe will make the quality of life better.

Care workers

Care workers rotas and working out what carers will do is crucial. It has been found that when carers are commissioned by statutory authorities there are sometimes problems with flexibility. A care plan gets written and care workers may be reluctant to work outside of that care plan or to vary what they do according to what is needed. Many of our carers have found that it is important to be substantially in control of the commissioning and designing of the care plan covering what gets done. This has been variously achieved by directly employing care workers and



also it can be helped by direct payments. With direct payments the key carer is given money which they can spend themselves and directly to employ care workers. It certainly is the case, for example, that if someone has just been to the toilet and a care worker then turns up with toileting on the care plan, that it is not necessary to re-toilet that the person. Rather, other appropriate tasks should be substituted. Sadly it is often the case that if toileting is declined, care workers will leave without having done anything else.

Hospital and respite care

Is needed in some circumstances and sometimes is appropriate.

Money

The cost of doing this in a week has been between £50 a week and £850 per week. We have once seen a package which cost more than £2000 a week but again in this circumstance there were thought to be considerable benefits for a patient who was not otherwise manageable in a continuing care setting. Certainly the weekly cost of care at home is, for the majority of people, lower than nursing home care. That the quality of life is better is perhaps a more compelling reason for promoting care at home. It is however heartening to know that such styles of care do not, generally, provide an additional cost pressure upon local health and social services.

Direct payments are useful. Continuing care money from primary care trusts should be available for complex management of dementia at home and has been provided for quite a number of patients.

Medication

Opiate analgesia is needed for some patients. It is not however frequently used and does not appear to be a mainstay of management of advanced dementia.

Antidepressants are frequently used: there is a very high rate of depression in patients with dementia. Anti-psychotics are also important. The high frequency of psychosis in dementia as well as the fact that behaviour problems in dementia are often driven by a psychosis which cannot be otherwise expressed should not be forgotten. The evidence base that distress and behaviour disturbance for some people with dementia responded to anti-psychotics is strong. These drugs do however cause side-effects (including stroke): the question therefore is whether or not the risk of side-effects outweighs the benefit accrued by effectively relieving the torment suffered by the patient. In a palliative care setting it must be acceptable to use drugs that can harm to alleviate severe distress which cannot otherwise be managed.

Antibiotics are important in some circumstances. Some antibiotics such as erythromycin and ampicillin are unpalatable and require larger volumes of liquid for about 20 doses. Others such as azithromycin only require four to six doses of low-volume medicine. This can be a real asset to dementia care when the patient is reluctant to take medicines. Similarly antidepressants and anti-psychotics which dissolve on the tongue can be very helpful. At times medicines may be put in foodstuffs [ref]. Anti-dementia drugs do not seem to be particularly useful. Memantine may help some of the behaviour disturbance.

Food and Diet



Good food nicely presented regularly and often, cut up into small pieces is helpful. Dogged persistence is also important: it may take a while for carers to get the hang of dietary support. A number of carers have found some particular "secret weapons". Guava Juice is high in calories and it doesn't seem to be acidic. Thickened soups peanut butter sandwiches chocolate baby foods have all been found by some carers to be particularly helpful.

One particularly important point is to remember that people with advanced dementia too often seem to have days when they don't particularly want to eat. Carers can be very worried about this: we often think that if someone does not eat three meals a day they were getting ill. We have found that if the patient does not want to eat and cannot be encouraged to do so without conflict and stress, it is often the best to just leave them be. If they don't eat one day they were often need a bit more the next day. Taking this approach may cause some trepidation because carers may feel they will die quicker from poor nutrition. In fact, we have generally found it is not the case. Patients have lived a considerable length of time after this approach has been taken..

Spiritual support

Perhaps the greatest spiritual need for patients is to feel loved and cared for by those whom they know and whom they value. Time spent sitting with a patient is important. It is essential to remember that no response from the patient does not mean that what has been said or done has not been felt. Many people who recover from episodes when they could not respond can recall and retell what was said and happened with surprising accuracy. We have seen patients very close to death suddenly show



evidence that they are aware (perhaps by making a sign of the cross or saying prayers) and other patients suddenly come out with lucid comments at times when they were not thought to be aware or hearing. The mere fact of being with someone having conversations with those around about day-to-day things is important and very positive for those with advanced dementia. Doing things at times of interaction is also important. Many people are not good at sitting doing and saying nothing. Feeding, personal care where possible and other activities are good things therefore for carers to do with their loved ones. Set prayers, reading from religious texts etc may be helpful. Specific prayers appropriate for those who are dying may also be helpful [ref].

The need for specialist teams



We think that the complexities around the managing of complex and advanced dementia at home require a special approach. It is widely accepted that the Macmillan style approach of community team in supporting patients at home with cancer is right. Even though the components of care provided by Macmillan teams can normally be provided by others within their knowledge and competence base, it is

well accepted that a specialist team does better. We believe that the same applies for dementia care. The challenges of managing complex and advanced dementia at home are significantly different from cancer care but the principle that a specialist team should coordinate services and the professionals is completely valid. We hope very much that we will see the creation of such teams and research into their effectiveness in the near future. A professional who is known to the patient and carer, and who will visit and monitor proactively has been strongly identified as a requirement by our research. Reactive visiting by primary care and others at times of crisis is simply inadequate.

Conclusions



If it can be done, the terminal care of dementia at home is a good idea. It appears to be for some, a better way for the patient. Dying people can continue to provide for those around them up to the moment of death. Perhaps at home with the family death is more human. Perhaps also bereavement is better.

Terminal care of dementia at home is not suitable for all and should not be considered as the only way. Residential and nursing care is needed for many people and there are times during an illness when people will require a different sort of care. We believe that it requires specialist teams although at the present time many are having to do this without any support of a co-ordinated nature.



Refs