

THE SPIRITUAL CARE OF DEMENTIA

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This article is based upon a talk originally given to Extraordinary Ministers of Holy Communion. It started with a recording of the Catholic Hymn “Hail Queen of Heaven”.

Spiritual care is widely recognised as being crucial in the care of those with dementia and those who are dying but the concept of spiritual care is poorly understood and poorly supported. Many are inclined to think that it is about making people feel better, providing comfort and support and enabling understanding. Whilst this is of course true, having thought this through this I became aware that that is not enough.

There must also be a religious and spiritual component for those who want and need it. As I thought about all this I came across a hymn which, for me, gives a sound and sensible philosophical and practical basis for understanding what spiritual care is. It comes from the Catholic “stable”. But it might just as well apply to any other Church or Faith stable with a bit of adaptation.

The hymn sets out how the gentle, kind and nurturing support, that all people of faith must wish to bring to those who are dying, must be set out alongside a clear understanding of the structures which that faith brings to provide such comfort and care. Put together, good spiritual care becomes a powerful tool for many.

It is true that the model may have some limitations for atheists, but for agnostics, we know that, as death and crisis nears, the acceptance of the possibility of the supernatural generally increases substantially. Even for atheists, we must allow those who are dying to hope in the future, even if they cannot believe that that future will simply not include them.

OUR LADY STAR OF THE SEA



There is a hymn which, for me, sets out that basis of understanding. It is a hymn to Our Lady, Star of the Sea called “Hail Queen of Heaven”. Of course it is not a hymn about dementia. It is in fact a hymn written in the 18th century at a time when sailors were regularly subjected to massive storms, while sailing in small wooden ships around the world. They routinely knew what it was to fear for their

lives upon the sea and routinely knew the prayers they would say as they hoped to survive the storm. On such nights, storm tossed sea sailors would look to Our Lady to keep them safe, to protect them and to bring them home safely to their families. The stars (especially the North Star) are the guide for sailors and it is natural therefore for Our Lady, who is the guide and protector of sailors at sea, to be seen as the "Star of the Sea". So it is that for sailors, who may be more regularly frightened and terrified for their lives than any others, Our Lady becomes their guide and protector in those darkest and stormiest nights.

Verse 1 **Hail, Queen of heav'n, the ocean star,
Guide of the wand'rer here below;
Thrown on life's surge, we claim thy care:
Save us from peril and from woe.
Mother of Christ, O Star of the sea,
Pray for the wanderer, pray for me.**

So the first verse of this hymn sets out the vision of Our Lady as the guide of the sailor thrown upon the sea. The verse pleads with her to save them from peril and from woe, bringing them safely home to port. But inevitably when people who work with dementia sing this hymn they are bound to smile a wry smile when they pray for the wanderer. Dementia is, after all, a condition which causes more wandering than any other medical illness.

Verse 3 **Sojourners in this vale of tears,
To thee blest advocate, we cry;
Pity our sorrows, calm our fears,
And soothe with hope our misery.
Refuge in grief, star of the sea,
Pray for the mourner, pray for me.
Mother of Christ, O Star of the sea,
Pray for the wanderer, pray for me.**

But here in Verse Three we see what Our Lady does for sailors at sea. What is it that the terrified man would look for in the mother of Our Lord? Actually he would look for someone who is able to understand his needs and able to understand how to help someone who is in such fear. Someone with dementia who is unable to remember or understand what is wrong with them will also look for the same qualities both in Our Lady and in those who set out to provide spiritual care for them.

We cry out to Our Lady to take pity upon our sorrows, to calm fears, to sooth our suffering and to give us hope. We ask Our Lady very simply to pray for us; to pray for the wanderer; to pray for the person with dementia. So it is that we should set out to provide care for people with dementia.

Verse three is literally a manifesto for the spiritual care of people with dementia.

THE NEED FOR SPIRITUAL CARE OF DEMENTIA

Of course it is simply a necessity that we should support and care for people with dementia. By doing so we not only help them, but we are helped ourselves. We are truly dignified by the care which we show to the most vulnerable members of our society. Just as Mother Teresa was hugely dignified by the love she showed to deserted children, we too are dignified by what we do for those who need us most.

To do this better we must of course understand the problems faced by the people we seek to help. We must understand about dementia and learn a little as to how we provide good care. Then we will be able to give effective spiritual care as well.

LIVING WELL WITH DEMENTIA

It is worth noting that it is quite possible to live well with dementia. For some, dementia is not actually a distressing illness. For some the worries of being responsible, running a family, worrying about finances and dealing with all the conflicts of life is reduced by becoming forgetful. Some people actually become happier as a result of dementia than they were before they got it.



Many more can indeed be perfectly happy with adequate care support and love. There is a massive difference between somebody who is struggling, hungry, with mouldy food in the fridge and an unheated house and somebody who is cared for, is warm and clean and has food and company. The latter may well be perfectly happy while the former will struggle greatly. The

difference between the two is procured entirely by right minded people giving good care. Dementia requires that we provide the right care and support to those who suffer it, so that they can live as well as possible and be comforted in their illness. Sometimes this can be excellently achieved in their own home and often with their own families. Other times it is best achieved in care homes. Sometimes it needs medication in addition. Wherever somebody with dementia is looked after, they really do require the best possible care.

DISTRESS IN DEMENTIA



For many others dementia is a distressing condition and here is a picture of a lady who was extremely distressed, struggling and frightened when we started caring for her. It is important that we do what we can to alleviate the distress and suffering of people like this. Just as surely as we must treat the pain of people dying with cancer, we must also seek to effectively alleviate the suffering of those with dementia. The good news is that we can usually do this fairly well although the reality is that we often fail to achieve this as well as we should: people often do not get as much care, assessment and understanding of their needs as they should.

This lady was living at home with her husband with good care and support, having had medication adjusted

appropriately and with the right assistance in terms of other carers and trips out etc. Her husband was delighted she was at home and would send me pictures such as this as a token of his gratitude. Indeed he was so pleased that he asked me to show pictures of her at talks like these.



It turns out that in fact the two ladies in the two slides are the same person. The surprise is that the top picture is her in 1995 and the bottom picture is her in 1997. She got better as a result of good care and a large part of her recovery was due to her return to her own home from the nursing home and the prescribing of appropriate medication etc.

For her the best care made her better but it is worth pointing out that often enough the best care will be to palliate (alleviate?) the distress, accept much of the decline which is associated with dementia and seek to provide the best comfort and care right through until death. Dementia is indeed a condition which causes death and on average people have about four and a half years after it is diagnosed. There is a wide variety of life expectancy (some live much longer) but the notion that dementia does not cause death is a false one. Dementia leads to inactivity, reduced resistance to illness, and an increased risk of strokes, heart attacks, pneumonia etc. Painful and difficult treatments become rightly limited and as a result death comes sooner to those who have dementia.

So it is right to be sure that we reduce distress in people with dementia when they are distressed but at the same time cherish and encourage them in every way we can.

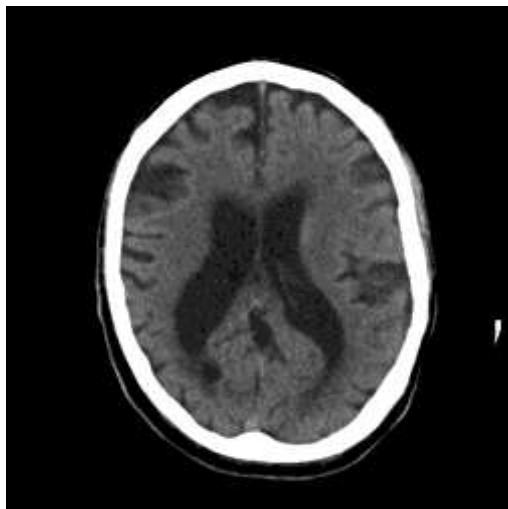
THE OPPORTUNITY FOR US TO CARE

But for everybody with dementia the illness provides an opportunity for others to support the sick and to help them to prepare both spiritually and socially for the end of their lives. Indeed this is an opportunity which is often not available to those who die suddenly and unexpectedly.

Dementia also requires anybody who gets it to accept care and support in ways in which they may previously have never done. Personal care, washing, cooking, being fed, accepting some of the indignities of being changed and having accidents are part of the illness (although that perception as an indignity is value based: accepting care can demonstrate the worth of the person cared for who is thus dignified).

In a Christian sense we must accept that all those whom we feed, all those whom we clothe, all those whom we visit when they are sick and all those whom we visit in care homes take the place of Christ as we care for them (Matthew 25, 36). Each person with dementia gives us the opportunity to love Christ by serving the people he loves so much. We are also supporting those whom he expects and hopes to take to him so soon.

WHAT IS DEMENTIA



Dementia is a progressive condition associated with the loss of brain cells. The underlying pathological process causes brain cells to die and the connections between brain cells to become reduced. As a result the entire brain functions less well. As well as difficulties in memory there are changes in personality, reduced ability to do things, reduced understanding and a reduced ability to communicate.

The picture shows a brain scan of someone with a combination of Alzheimer's type dementia and a vascular dementia. The amount of brain (which is grey) is reduced. The black shadows in the middle are the ventricles which are enlarged and the black lines around the outside show the increased gap between the folds of the brain. This person has a moderate dementia. In severe dementia changes are often more marked.

In Alzheimer's disease you see microscopic things called Neuro-fibrillary tangles and plaques. It is these microscopic processes which cause the brain cells to become disordered and to die.

In vascular dementia small blood vessel disease causes tiny infarctions (small areas of cell death) and hundreds of thousands of these areas combine together to produce a

similar effect. If there is a difference between the two dementias, it is perhaps that insight is often a little more present in vascular dementia and then maybe sometimes more focal deficits in ability.

Most dementias are a mixture of those two types.

There are various types of dementia. We have already mentioned the Alzheimer's type and the vascular type. There are dementias associated with Parkinson's disease, and also rarer forms of dementia such as Picks disease or fronto-temporal dementia.

It is worth just mentioning that it is the Alzheimer's type and the Parkinson related dementias that appear to benefit most from the memory improving medications.

NEED FOR CARE IN DEMENTIA

The greatest need in dementia is really good care. Without care people will suffer in pain or distress and discomfort. Support is so much more effective than any other medication or treatment. Sensitive support, understanding, communicating well and respecting and loving is absolutely essential.

Good treatment does include memory improving drugs but will also include excellent medicine optimising all the other conditions the patient has. In addition, alongside the highest standards of care and support, distress must be alleviated. Sometimes this requires medication. Other times it just requires good quality care.

THE NEED FOR HOPE, TRUST AND FAITH

Of course all those with a life limiting illness should be able to have hope and trust that their care will be excellent and those looking after them will do the very best they can.

In all honesty, patients with dementia have the right to expect ongoing care and support from both professionals and clerics, as well as from those who value their faith and appreciate what their faith means in terms of the call to charity.

People with dementia must always be respected and should not be seen as an encumbrance. I have seen people with dementia in the last days of life continuing to contribute to those around them and continuing to function as a member of a family. We too easily conclude that those who are dying no longer serve those who will be left behind. Even at the very end of life, we can see a two way relationship between the patient and carers.

COMMUNICATION

It is worth mentioning that communication is a really important issue in dementia care. Anyone visiting the sick needs to take time and they need to be relaxed. Try not to be

too complicated. It is a real blessing to be able to enjoy the person you are with. If you know more about their background this becomes easier. It makes it possible to do things differently and people with dementia remember the past much better than they remember the present. In this context discussion about the past may well be helpful.

A gentle chat about Church last Sunday will remind the individual of their trips to Church throughout their life. Gentle chats about anything relatively trivial will give a calm and relaxing atmosphere enabling the best communication and the best quality of interaction.

People with dementia become distressed when they cannot understand. They equally become distressed when they cannot work out how to reply to somebody. So it's really important to try and avoid arguments. It's also useful to try and put the answers into questions. Rather than saying "do you want Holy Communion", it is perhaps a little better to try something like "it's my day for visiting you and so I brought you Holy Communion." The latter may well get a far more positive response.

IT IS NOT ENOUGH TO BE JUST CARING AND NICE

It is very definitely not enough just to be nice caring and comforting. Dementia brings the need for real changes as life is truly changed. Dementia also brings the opportunity to think and pray about these changes. Given that someone with dementia is no longer as able to practice their faith by themselves, it is really important that we provide them with the opportunity to do so.

By doing so we will help to value and respect them as we should. If we leave them alone, we neglect our Christian duty.

SPIRITUAL CARE OF DEMENTIA

Indeed most of all dementia is a social and spiritual illness. While we focus mainly upon the medical, it is about a profound change in life and also unquestionably about the final journey of individual sufferers towards God. So if we neglect the spiritual, we fail our patients.

In fact health services almost always forget the spiritual and will almost always only send for the Church at the last moment if they ever do at all. Priests and Church visitors are excluded from the confidential network of hospitals. Therefore they are never told there are Catholics in hospital: they must tell us themselves. People with dementia cannot do this and nor can other very sick individuals. It is really important therefore that we keep an eye open for all those whom we know so that we are informed when they go into hospital and when they go into care so that we can provide the right input and right support for them. What a tragedy it is when the sick and vulnerable members of our society are thus denied access to the spiritual care they should have a right to receive.

I remember when I first qualified taking a couple of people to Mass on Sunday at a time when there was a Mass in the hospital. A few days before a lady had collapsed

unconscious with a cardiac arrest. Happily she survived, though she was very ill. Seeing me taking others to Mass she asked if I could take her too. I told her “no” because she was too ill. She was still there the following Sunday and she called me over to ask if I would take her this week. After Mass she burst into tears and told us that she had not been to Mass in 40 years. It was a beautiful afternoon!

SACRAMENTAL AND PRAYER SUPPORT OF DEMENTIA

We should not forget that there is plenty of evidence that prayer works. Even the doubters at the very least cannot say that prayer does not work. So we need not apologise for praying with the sick and we need to be able to help some people to pray and to guide them towards prayers that fit the needs that they have.

Of course if prayer works (which we believe that it does), it does more than to just comfort or make us feel good. It can make a real difference and lead to real changes for individuals.

SACRAMENTS

Beyond that of course the sacraments are real means of actual concrete grace and these must not be neglected or denied to the sick. In baptism we are born to Christ, and in Holy Communion Catholics believe that they truly receive the body of Christ. In Confession their sins are forgiven (by Christ) and in the Anointing of the Sick they are given the strength, peace and courage to overcome the difficulties that go with the serious illness or frailty of old age as well as prepared in a special and spiritual way to meet Our Lord. Sins are also forgiven by the sacrament of the Anointing of the Sick

Through all the sacraments we are helped further along our path of redemption by Christ our Saviour.



CONFESSION

Confession does require an awareness of sin, an understanding of repentance, and the ability to articulate both the sins and the repentance. Confession is quite possible to do early on in dementia but in advanced dementia it will really become quite impossible.

So, let's think about things early rather than leave it too late. Let's consider offering confession to those

with early dementia who are Catholic rather than forgetting the spiritual needs of our patients until it is

Practical tip

Offer confession early if you think someone is able to understand and confess their sins.

too late.

A note here - it is worth mentioning that people do some remarkably inappropriate things when they have dementia. Perfectly decent kind and saintly people will start hitting, spitting, swearing and stripping off. I have had wonderfully good Catholics telling me to do things in very colourful language. These are almost certainly not sins. They are not wilful acts but they reflect acts of disordered minds and we may console ourselves and their families with the thought that they are done in the innocence of dementia. Indeed in the circumstances people with dementia are probably just as innocent as a one-year-old.

So offer Confession early while people can understand the issues of dementia.

THE ABILITY TO RECEIVE HOLY COMMUNION

To receive Holy Communion requires the proper dispositions for receiving Holy Communion. It also requires an understanding and belief that this is something special. It is not necessary to have the full understanding that the host is truly the Body of Christ although this is, of course, desirable and hoped for in communicants who do not have dementia. In the case of someone with learning disabilities it would only be necessary to establish that they knew the difference between the Eucharist and ordinary bread - "a belief that is it something special". As a result it may not be suitable for those with very severe dementia and it can be problematic for people who spit it out. Generally one is likely to assume that if people spit out the host they are failing to understand what is offered. If there is doubt, then perhaps a very small fragment of a host is a good idea. Our Blessed Lord's body is equally present regardless of the size of host given.

If you were to ask a person who is a devout Catholic whether they would wish to continue receiving Holy Communion if they reached a point where they unwittingly spat out the sacred host, they would surely say that they would not wish to receive the Sacred Host in those circumstances. This is not a question of a person being "unworthy" but of respecting the dignity of someone who has always lived a devout Catholic life.

On the other hand I once took a lady to Mass with a quite severe dementia which caused her quite a lot of distress. She chatted all the way through Mass and looked somewhat distressed. However, at Communion she stilled and became calm. It was not only me who thought that a significant spiritual change came upon her at the time she received Communion.

So the bar to receiving Communion is really quite low but if you clearly expect that giving it will cause the Host to be spat out etc., then perhaps it is best to pray and not actually give Communion.

Finally if the Host is spat out then you can probably consume it yourself. You may not like doing this but it is pretty safe and the infections you might get very rare. There is no evidence that you could contract dementia by doing this and it will protect the Host from further indignity. The alternative is (remembering it to be truly the Body of Christ and thus due very special reverence) to take it back to Church and to put it in a glass of water beside

the Tabernacle until it no longer has the form of bread. By then it can be disposed and the recommended method for this is to dispose of it into the sacrarium or directly into the ground if the Church does not have one, and not down a drain etc. While to some such caution may seem daft, it does in fact enable us to show the extreme love and reverence we wish to have for Christ our Saviour.

Practical tip

If the Sacred Host is spat out, you can probably consume it yourself. You may not like doing this but it is pretty safe and the infections you might get very rare. There is no evidence that you could contract dementia by doing this and it will protect the Host from further indignity. If in doubt, give a small fragment not a whole host.

ANOINTING OF THE SICK (FORMERLY REFERRED TO AS EXTREME UNCTION")

The sacrament of Anointing of the sick is for people with serious illness and life-threatening illness, including old age. It can be received more than once during the same illness if the patient's condition becomes more serious, or in the elderly whose frailty becomes more pronounced. It is best not left to the last minute. Clinicians and Extraordinary Ministers should seek to ensure that those who are unable to ask for Anointing themselves are provided with the opportunity to receive it. [1]

PRAYER



last sign of awareness that she ever gave.

Prayer is so important. We remember from Verse Three of the hymn we discussed at the beginning, the importance of comforting and soothing the worries and fears of our patients. Prayer is a practical thing that we can do and even in very advanced dementia we find patients responding to it, joining in and doing other acts of devotion as a result of the prayer they are surrounded by. I remember a lady the night she died: the family said prayers at her bedside and during the last decade she made a tiny but perceptible sign of the cross. Many others have shown similar signs of response. It was the

Remember that even when people are unable to respond they may well hear and understand what is happening. This has certainly been the message given by people who have been apparently unconscious and recovered (from conditions other than dementia which you cannot recover from)

Remember too the widely held hypothesis that perhaps prayer may be more effective when it is offered by someone who is really suffering.

There are many forms of prayer but some of the simplest and most familiar will be good. The Our Father, the Hail Mary, the Creed. The Rosary takes a little longer. Actually that may be quite a good idea because 20 seconds of prayer may not be enough to produce the calm understanding and the oneness with God which the Rosary can offer. So if someone cannot receive Communion etc., then a few decades of the Rosary said at their bedside may well be really helpful.

For others, reading from Scriptures or text from the writings of the saints may be really helpful.

PRAYERS FOR THE DYING

There are some beautiful prayers in the St Andrew Bible Missal for those who are dying and these are available on the Internet and easily downloaded. They help both the dying and bereaved. The litany of prayers has been said by many people who we know and can be very helpful.

The prayers for those who have just died give the opportunity to see how the soul is carried forth from the body to meet Our Lord and the final judgement. Of course it is right to pray for these people on their last journey and to pray for their forgiveness by their Saviour.

You can find some prayers which many have found to be really helpful at http://www.cmq.org.uk/Miscellaneous/Prayers_for_the_dying.pdf [2]

Or just put "catholic prayers for those who are dying" using exclamation marks into Google and you will find it.

LATE ILLNESS AWARENESS

People who are dying may often seem to be unconscious or semi responsive. We know that often enough there is good awareness and that even though there may be no response, they will participate in prayers and listen. The prayers below may be said therefore, firstly because they are effective prayers to help the dying on their journey to meet Our Lord and secondly because, if said aloud in the presence of the person dying, that person will know those who care and love them are near. They may of course be said more than once, though the time they allow you to spend praying with the person who is dying will mean that frequent repetition is not required. [extracted from Catholic Prayers for those who are dying or who have just died]

We mentioned earlier the late illness awareness of some of the patients we have known.

Assume the patient can always hear you and be aware until they are actually dead, by which time they may see you praying for them as their spirit leaves their body. Pray with them and for them.

Sometimes use words and set prayers. But sometimes use quietness too, though words give a structure to communicate the peace of Christ.

MISTAKES WE MAKE

I think I should also mention some of the mistakes we make in terms of looking after people with dementia and other mental illnesses. Christianity is a wonderful thing which brings wonderful support but we do have to understand when we get things wrong.

Firstly of course there is the question of the sins of our Fathers and the sins of our past. Our Lord specifically discounted the hypothesis that our illnesses are caused by the sins of our Fathers. Similarly most illnesses simply arise as a result of illness and not the things we do wrong. Mental illness is really not very different from other illnesses.

Sadly many people subscribe to the idea that depression is in fact a sign of emotional or spiritual weakness. This can lay a very heavy extra burden upon those who suffer such illnesses.



So I do find myself feeling very distressed when I see a poster like the one in the picture stuck up outside a local church and saying "If you have no hope then you have not found Jesus". To suggest that those who have a depressive illness have not found Jesus is to tell them they are to blame for their depression.

This is really deeply insensitive and quite unchristian. It is factually wrong and misses entirely the duty we have to care for those who are ill. Depression is a major illness which does indeed remove the hope of those who suffer it. I have met many good and wonderful people of strong faith who, through having got a depressive illness, have indeed lost their hope in the future and even lost hope of salvation. There is a grave cross and we should not add to it by telling them they are imperfect or bad Christians.

Depression is in fact a medical illness. It is not a sign of a lack of faith but is actually in most people, a predisposition to illness caused by either inbuilt or inborn traits or acquired illnesses. The majority of depressions in old age arise from small blood vessel disease in the brain. So we need not concern ourselves with working out why people are depressed etc. Schizophrenia too is an illness which has an essentially inborn cause. It is not an illness which you get because you have bad parents or because you do bad things yourself. If we get pneumonia we consider ourselves unfortunate. It is far easier to give ourselves pneumonia than it is to give ourselves schizophrenia or depression.

In depression people may start to believe and worry about awful things. In the elderly their past will come back to haunt them. It's best to remember this. The preoccupations, beliefs and worries of a depressed person are not the cause of the illness. The illness causes them to become preoccupied about some of the bigger worries they had from earlier life. We must not attribute illnesses in old age to things from early life.

In my experience people of faith show two versions of severe depression. In one form they merely conclude that their sins have been so awful that they cannot possibly be redeemed and they become convinced of their damnation. Even a minute tax error in the early 1950's can provide enough evidence to support an unshakable belief in their damnation. The other group merely lose their faith and conclude that all they ever did was in vain. Either form of depression is a huge torment. Tell them it is their fault for lacking faith and you merely enhance their suffering.

Dementia is not a punishment from an earlier life, it is merely an illness acquired in old age.

Remember too that pain due to a broken leg would never be treated by love, a hug and a cup of tea. We will splint it and mend it. The pain of that leg may be reduced a little by love and good care but it will not be effectively treated.

In the same way the distress of dementia also requires good effective treatment along with the right love and support. To try and treat the distress of dementia without the right medication should be just as unacceptable as trying to treat a broken leg with prayer but no splint.

FINAL TIPS

- Be confident but humble.
- Be confident that by caring you do what is good and what God wants.
- Be humble knowing that in doing your best, you will both succeed and get it wrong.
- Try and find out a bit about the person you're caring for: it will help you care better.
- Do not fight.
- Offer care and love.
- Cherish the dying and love the sick.
- In the midst of the work and strain of it, try to enjoy the privilege of providing care for the person who is in your care.

**Sojourners in this vale of tears,
To thee blest advocate, we cry;
Pity our sorrows, calm our fears,
And soothe with hope our misery.
Refuge in grief, star of the sea,
Pray for the mourner, pray for me.
Mother of Christ, O Star of the sea,
Pray for the wanderer, pray for me.**

REFERENCES AND FURTHER READING

[1] Do I have a duty to arrange for my Catholic patients to receive Communion/Sacraments for the dying? Catholic Medical Association

<http://www.catholicmedicalassociation.org.uk/announcements/do-i-have-a-duty-to-arrange-for-my-catholic-patients-to-receive-communion-and-sacraments-for-the-dyi>

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[5] <http://www.hopeforhome.org.uk>

[6] Assessing and Managing Distress and Pain in Severe Dementia

<http://www.dovehouse.org.uk/document.doc?id=805>