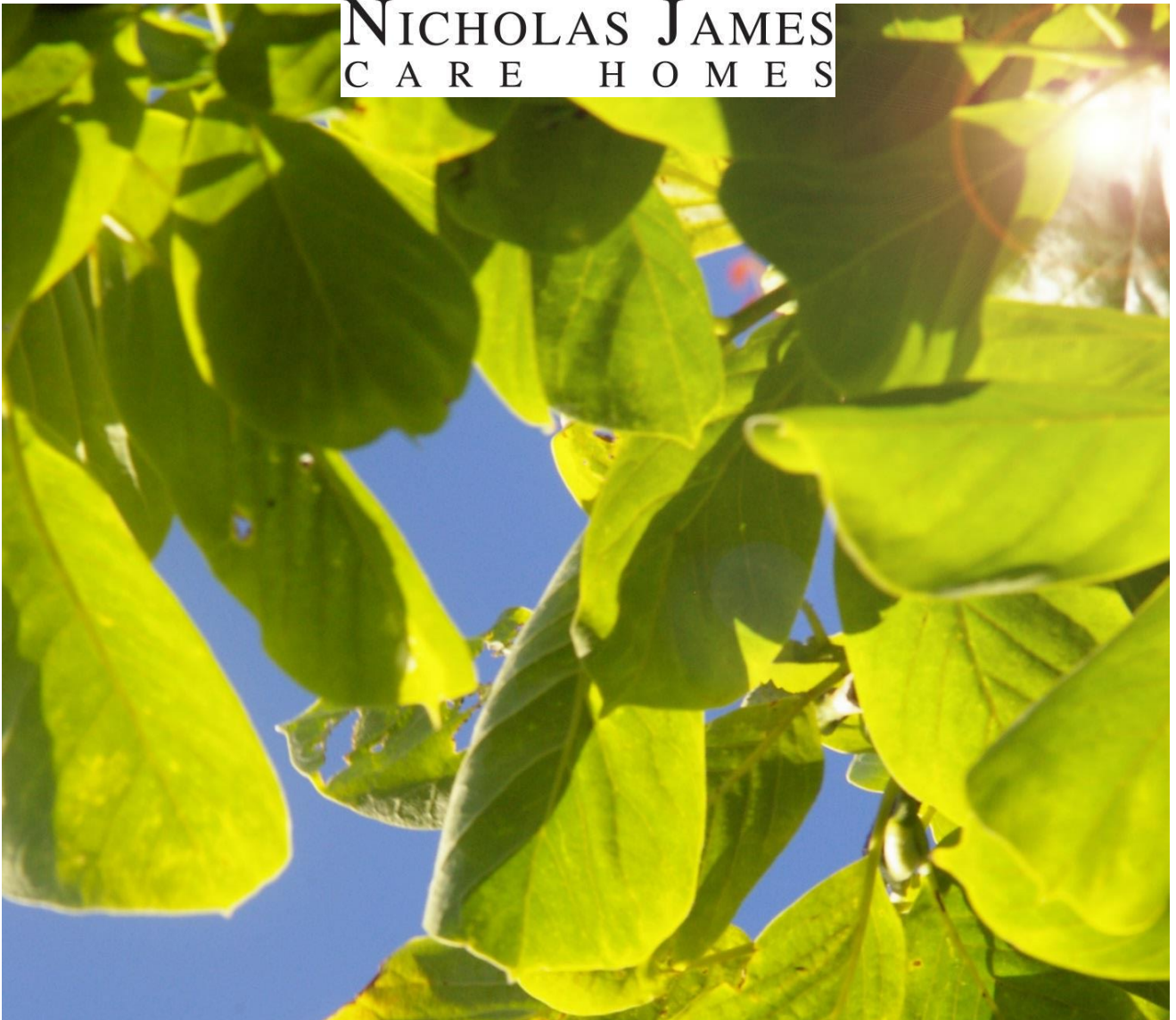




NICHOLAS JAMES  
CARE HOMES



Nicholas James Care Homes Ltd  
End of Life Care

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# About This Booklet

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The time when someone is approaching the end of their life is inevitably difficult and emotional time for everyone. Nicholas James Care Homes are committed to doing all we can to ensure that your loved one's time at this stage in their life is dignified and that they have a 'person centred death'.

This leaflet has been designed to give practical help and guidance on End of Life preferences, what to do to prepare, what to possibly expect towards the end of life and what you do when a loved one dies. We want to make sure that our Services Users, their families and friends are given as much information and support as possible during this time.

## What do we mean by 'Person Centred Death'?

From our experience ensuring that planning and talking about your loved ones preferences, what their wishes are before and after death can help to ensure that this last part of their journey is dignified. We also find that for the person's family and friends knowing that their loved ones preferences and wishes have been met allows them to glean a sense of comfort. Through this booklet, staff training and our core ethos of the 6 Cs we aim to make a positive difference in the experience of our service user and their families.

Firstly we will look at the 'End of Life' preferences that either your loved one or yourself might choose. These preferences although something that may prove difficult to go through will prove a comfort after your loved one has passed.

We will go over what our Nursing and Care Communities have put in place, the training that our Nursing and Care Teams undertake to ensure that your loved ones needs are met during this time and that their dignity is upheld at all times.

Importantly this leaflet will also cover the changes you may see physically and psychologically in your loved one during the final stages of 'End of Life'.

It isn't always possible to predict what will happen in the last few months, weeks or days of your loved ones life. However importantly this leaflet will try to explain some of the physical and personal changes you may notice during this time.

It will also look of the end stages of Dementia, what changes you may see and how it may develop.

Finally the leaflet will give some advice and guidance on what happens after your loved one passes away and what happens next.

Ultimately our hope is that this booklet will give guidance and reassurance whilst answering sensitive and difficult questions.

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# End of Life Care at Nicholas James Care Homes:

**What does the term 'End of Life' mean?** The term is given to someone who has been diagnosed with an incurable disease or someone in the final stages of a progressive and advanced disease.

**How long does 'End of Life' care last?** It can last days, weeks, months or even years, it is not always possible to put a time frame on this period in someone's illness.

There are many aspects in creating a person centred End of Life Care Plan for an individual. At Nicholas James Care Homes, we strive to provide 'good end of life care' that is person centred and based on a holistic approach for each individual; covering all aspects of their wellbeing including the physical, psychological, social and spiritual needs; which also includes beliefs, culture, ethnicity, religion, sexual identity and sexuality. It is also important to us to ensure their choices and beliefs should be respected and remain stable throughout. The care planning involved in looking after our service users is ever evolving to enable us to meet their possible changing needs. We work as a team, working closely with GP's, District Nurses, other external medical professionals, outside agencies and organisations to ensure that we provide the best care possible. Through this type of partnership approach to 'End of Life Care' we are ensuring the quality of someone's life and their death rather than on the length of time someone lives with us.

We are always looking to enhance the 'End of Life' care within our communities and our managers are always developing their training, knowledge and looking at new research. This also includes the new *'End of Life Care Core Skills Education and Training Framework'* by Health Education England, Skills for Health and Skills for Care.

We take the development of our Nursing and Care Teams seriously and not only provide them with an ongoing training matrix, with courses that are run on a yearly basis but we also ensure that we look to enhance our staffs knowledge through new and innovative training. Such as our own virtual Dementia Training, developed by our senior and experienced award winning management team. We also have Palliative Care leads who are encouraged to attend more in-depth training with their local Hospices and Health Care Authorities, whom we work closely with.

Importantly our care does not only extend to the person we are looking after but we are also there for the families and loved ones; we try and ensure that during difficult times we are there to offer support, guidance and advice. But all times giving you the privacy and respect that the service user and loved one needs.

A recent addition being rolled out (2018) within our communities are our 'Butterfly Baskets' or 'Baskets of Love' which are designed to give comfort to our resident and their loved ones in the final stages.

For 2018 and onwards we will be gradually rolling out the Gold Standards Frame work throughout our Residential and Nursing Communities. The frame work will give us a greater and enhanced holistic approach to the services we offer.

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End of Life Preferences:



End of Life Preferences are important to understand and at Nicholas James Care Homes we will always try to engage and introduce our 'End of Life' section of the Care Plan either with the service user, their family and loved ones as early as possible. Our Service Users care plans are person-centred and tailored to ensure that their needs are met and followed through.

Deciding on the preferences and making decisions may be difficult and emotional for the service user and their loved ones; however experience has taught us that having these important and personal details in place ensures that when the time comes it is a comfort not having to think of the answers or trying to guess what that person might have wanted.

Everyone's approach to death and dying is different, not everyone has thought about these questions before or they may have everything planned. No matter how your loved one feels about answering these questions please be assured that our trained and caring staff are on hand to ensure that these details are recorded for when the time comes. It is during this planning stage we reinforce the importance of allowing the individual person to make choices and decisions about their 'End of Life Care'

Some of the questions that you and your loved one may be asked to fill in are the following;

*"Do you feel it would be in your relatives best interest to have a do not resuscitate (DNAR) in place?"*

*"If your relative's health deteriorated do you feel it would be in their best interest to receive treatment in hospital, or be cared for within the home with the input from relevant multidisciplinary teams e.g. palliative care team?"*

*“Where would your loved one prefer to pass away, either at the home, a hospice or in hospital”?*

*“Does your relative have a pre-paid funeral plan in place?”*

*“Is there a preferred funeral directors your relative and family would like to use?”*

*“Has your relative expressed whether they would like a cremation or burial?”*

*“Are there any religious or cultural practices that your relative would like carried out during their end of life care?”*

*“Is there any wishes you’re relative has expressed in the past regarding their end of life care?”*

*Is there an advanced directive?*

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End Stage Dementia:

Although Dementia is a terminal illness and shortens life expectancy it is very difficult to know how long someone with dementia can live for after diagnosis; especially if there are other life limiting medical conditions such as e.g. Diabetes, Cancer.

We treat and care for all stages of Dementia within our Nursing and Care Communities. Making use of our high training standards, associations with multiple Dementia organisations and multi- disciplinary medical teams to support us in caring for a service user who may be in the end stages of Dementia.

We define the 'End Stages' of Dementia through a number of factors.

When someone's Dementia is entering in to the final stages we often see that physically they;

- Become frailer
- Lose the ability to stand, sit up or walk
- Become bedbound
- Have bladder and bowel incontinence
- Have difficulty in swallowing
- Lose of communication
- Become more prone to infections such as urine and chest.

You may also find that they become more confused, have decreased appetite and fluid intake, that they don't recognise you and that they lose interest in daily activities.

Someone's Dementia can change throughout their illness and it appear that they are in the end stages but live for many more months. It is this uncertainty and prolongness of the illness which can be distressful for loved ones to witness. This is why as a company we have focus on giving our staff excellent Dementia training which enables them to try and help families understand these stages of Dementia.

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Nearing the End:

## Nearing the End:

The experiences and journey of the last few weeks of someone's life can vary and we do all we can to prepare and meet our service users needs during this time.

Although you cannot predict physically and psychologically how someone will spend the last few weeks/days of their lives, these are some of the natural signs that someone is nearing the end of life.

Physically the person may deteriorate and their mobility decreases

They may prefer to spend more time in bed or become bedbound

Spend a lot of the time sleeping and when awake they are drowsy.

When awake they may not recognise or remember where they are

They may feel like they are in a dream state and or hallucinate when conscious.

Their appetite for food and fluids may decrease as the body ceases to need food as it begins to shut down.

### | Managing Pain |

For any loved one of someone who is nearing the end of their life, a concern is that they do not suffer and are not in pain. Ensuring that your loved one is free from pain during this time is crucial and whether your loved one is in one of our Residential or Nursing Communities our highly trained and qualified Nursing and Care Teams will work with GP's, District and Hospice Nurses to make sure we have everything in place to ensure we manage the pain.

## | Maintaining Oral/Mouth Care |

As service user become progressively unwell they will need assistance with oral hygiene.

This is an important aspect of end of life care and is something that family members can be taught to do if they wish. This may help lessen their distress at not be able to feed their loved one.

## | Management of Nausea and Vomiting |

Nausea and vomiting are common symptoms near the end of life that can cause substantial physical and psychological distress for the service user and their families.

Plenty of fresh air can be helpful as well as avoiding strong cooking smells; cold rather than hot meals may be helpful. Relaxation can help as anxiety can make nausea worse.

## | Management of Respiratory Secretions |

Noises caused by upper airways secretions are heard in approximately 50% of those NEAR end of life. This is caused by air passing through the airways with secretions present as the service user is unable to swallow or clear them.

Repositioning the service user is often helpful in decreasing the noise: place the service user on their side with upper body elevated

Good oral/ mouth care can also be helpful.

## | Relieve Pressure Points and Prevent Pressure Sores |

The skin is the one of the first organs to fail in end of life patients. Skin assessment should be done regularly and document all areas of concern consistent with the wishes and condition of the patient.

Consultation with a specialised healthcare professional is recommended for any skin changes associated with increased pain, signs of infection, skin breakdown.

Although death is a normal process, it can be frightening not only for the person but for their loved ones too so it is only natural to worry or be fearful. What we will try to do is put your mind at ease and be on hand for advice and reassurance.

Every Service Users personal circumstances are different; whether family and loved ones are able to be there every day, whether they live away or maybe there isn't anyone. We will always attempt to ensure that we follow the wishes of the service user and their loved ones. We understand that families can't always be there and how important it is to keep families and loved ones up to date. And, if possible to be there when the times comes; if that is the service user's wishes. It is at this time that you may want to contact any religious or spiritual advisors you may wish to visit your loved one.

## | Final Moments |

For many dying is peaceful and quiet. The service user will normally slowly slip in to unconsciousness completely or spend time slipping in and out of consciousness. Again, at this time the comfort and dignity of the service user is of paramount and our Nursing and Care Teams will continue to monitor and ensure the best possible care is given.

It is important to remember that although your loved one may not be conscious or may not be able to communicate they are probably still able to hear. Often talking and reminiscing about your loved one or playing their favourite pieces of music can be comforting for both the service user and their families/loved ones.

You will possibly start to notice a change in breathing, it may become irregular, shallow with longer gaps between each breath. It may also become noisy, this can be due to a number of physical changes the body is going through as it begins to shut down.

You may also see other physical changes such as your loved ones hands and feet becoming cold or changing colour; they may also be sensitive to the touch.



Although these signs of the body shutting down and dying can be distressing for loved ones, it is important to remember that it isn't normally distressing for the person who is dying.

At the final moments, for most people it is peaceful as their breaths become shallower and slower with long pauses taken in between each breath. It is very difficult to know how long this period will take, for some it may take minutes for others it may be longer. They will finally stop breathing altogether. It is at this point that the body will normally relax and your loved one may look at peace.

After your loved one has passed away you may want to take time to be with them or you may choose to have quiet reflection on your own.

Whichever you choose our staff are here to support you.

If you are unable to be with your loved one when they pass away we will ensure that their chosen 'End of Life' Preferences are fulfilled and contact you to inform you of their passing.

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What To Do Next:

## What to do first:

### *If death was expected.....*

Contact the family doctor who cared for them. If the doctor can confirm the death they will give you:

A medical certificate which states the cause of death. This will be in an envelope addressed to the registrar

A formal notice that says the doctor has signed the medical certificate and how to register the death.

### *If death was unexpected.....*

Contact the family doctor who will advise if they have reported the death to the coroner.

The coroner may decide that there needs to be a post mortem and an inquest. This should not delay when you can have the funeral.

Contact the coroner's office if you want advice or information.

The coroner may issue a notice known as 'Pink form B (form 100B)

This form shows the cause of death so that the death can be registered.

The coroner will give you a certificate for cremation or order for burial (form 101) which allows the funeral arrangements to go ahead.

## | How to Register a Death |

A death must be registered with the registrar of births and deaths. If the death has not been referred to the coroner, you should contact the registrar as soon as possible.

The death must be registered within 5 days, unless the registrar says this period may be extended.

If the death has been referred to the coroner, it can't be registered until the registrar has received the coroner's permission to do so.

You will need to go to the registrar's office in person to tell them formally about the death. You can go to any registrar office in England and Wales but if you use a registrar out of area this may cause a delay in arranging the funeral.

*When you go to the registrar take:*

The medical certificate which shows the cause of death

The person's medical card, if possible

The person's birth and marriage certificates if these are available

*You should tell the registrar*

The date and place the person died

The person's usual address, any benefits

The person's first names, surnames/maiden names

## | People to Inform |

The person's solicitor

The doctor

The person's bank, building society, post office

Pension service

## |Arranging the Funeral|

Do not make final arrangements until you are sure you do not have to report the death to the coroner.

Find out if there is a will, as there may be details of what the person wanted for their funeral arrangements.

If you arrange for a funeral, you are responsible for paying the bill, so first check where the money will come from and if there will be enough to cover all the costs.

If you arrange a funeral service in line with a particular religion, you can seek advice from the minister of that religion or the religious organisation that the person who has died belonged to.

If a funeral director has not already been identified in the 'End of Life' Preferences you will be able to find most funeral directors listed in the Yellow Pages or online; also friends, family or the doctor may be able to recommend a local company with a good reputation.

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# Useful Contacts and Advice Lines:

- Dying Matters  
<http://help.dyingmatters.org/>
- Alzheimer's Society National  
Dementia Helpline England, Wales and Northern Ireland: 0300 222 1122
- Cruse Bereavement Care: 0808 808 1677
- National Association of Funeral Directors: 0845 230 1343

## |References & Acknowledgements|

'End of Life Care; Core Skill Education and Training Framework' (Skills for Care, Skills for Health, NHS Health Education England, February 2017)

'End-of-Life Care Fact Sheet' (Alzheimer's Society, June 2014)

'End of Life: A Guide', (© Macmillan Cancer Support and Marie Curie Cancer Care, June 2013)

'What to do after a death in England or Wales'. (Department for work and pensions 2009)

'What To Do Following A Bereavement' (Ashcroft House Residential Home)

Images:

*Nicholas James Care Homes Ltd*

*Abigail Draper B.A*