END OF LIFE CARE TOOLKIT

Forward – From the Newham Training Hub EoLC Training Working Group

The aim of this tool kit is to act as a resource for Health and Social Care Professionals who are supported individuals who may be in the last year or months of life. It is designed as a reference guide that can be used as all health and social care professional.

Throughout the toolkit, there are a range of links which will provide you with more information, links to e-learning and down leaflets that you can download. We hope you find this toolkit helpful, if you have any resources or information that you think should be added please sent it to nelondon.newhamtraininghub@nhs.net

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GLOSSARY OF TERMS

ACP	Advance care plan
PPC	Preferred place of care
PPD	Preferred place of Death
UCP	Urgent care Plan – May be referred to as Better as it is hosted on the 'Better' platform
ADRT	Advance directive to refuse treatment
DNACPR/ DNR	Do not attempt cardiopulmonary resuscitation decisions If your heart or breathing stops, the healthcare professional will not try to restart it. The DNACPR decision is usually made by the patient and the healthcare professional.
Palliative care	If you have an illness that cannot be cured, palliative care aims to support people to be as comfortable as possible by managing pain or other distressing symptoms. Palliative care considers care for the whole person rather than just their illness, so it looks at the physical, emotional, social or spiritual need of the individual. Palliative care is not just for the end of life – people may access palliative care while their illness is still being treated.
End of life care	End of life care is support for people in the last month or year of life. It should help the person live as well as possible until they die and support people to die with dignity. End of life care should focus on supporting people to live well. This includes giving them the opportunity to express their wishes for future care.
SPC	Specialist palliative care. Specialist palliative care teams care for patients with complex symptoms or problems that cannot be solved or treated by their usual healthcare provider. Not all dying people need support from Specialist palliative care teams, many can be cared for by their usual healthcare provider.
TEP	Treatment escalation plan – this is a document used mainly in acute hospitals. It allows clinicians and patient to describe ceilings of care. E.G the individual is for ward-based care and not for transfer to ITU if their condition deteriorates or to have oral antibiotics only.
Respect Document	The ReSPECT process creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices. ReSPECT | Resuscitation Council UK
LPA	Lasting power of attorney There are two different types of LPA: A personal welfare LPA is for decisions about health and personal welfare. An Attorney for personal welfare can only act when you lack the capacity to make a particular decision yourself. A property and affairs LPA is for decisions about financial matters. an be used when you still have capacity unless you have specified otherwise Make, register or end a lasting power of attorney - GOV.UK (www.gov.uk)

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SERVICES AVAILABLE

There are a number of services available to support you as you approach the end of your life. Some are universal for those with health and social care needs and some are specific to end of life care. GP's and the local community nursing service provide most of the care for people at end of life.

Hospices

Hospices provide care and support either in the hospice or in your home. Their aim is to ensure you are comfortable by treating your symptoms and enabling you to live your last days as fully as possible.

Richard House Children's Hospice
Richard House Drive, Beckton, E16 3RG
Call:020 7511 0222
info@richardhouse.org.uk

St. Joseph's Hospice-provides care and support to people living with a range of life limiting conditions, this includes inpatient beds, community palliative care and a wide range of day services including day hospice, counselling, benefit advice and carer support. Healthcare professional can also obtain support and advice on symptom management 24/7. It also provides child and adult bereavement services for City and Hackney residents.

St Joseph's Hospice, Mare Street, Hackney, E8 4SA Call: 020 8525 600024/7 Advice and Support line 0300303040
Email: **info@stjh.org.uk**

Marie Curie – provide planned night sitting service and an overnight rapid response team 10pm- 8AM 7days a week. The following clinicians can refer to this service: GPs**,** District Nurse; Consultant; to refrer lat.mcnewhamnightresponse@nhs.net or 07714847133

Bereavement support in Newham and Tower Hamlets is provided by mind people can self-refer by phoning 020 7510 1081 / 020 7510 4268 or by emailing nbs@mithn.org.uk

NHS Community Palliative Care Services (such as Waltham Forest Community Palliative Care Team and Redbridge Community Palliative Care Team) - These services have teams of professionals made up of nurses/doctors/complimentary therapists and social workers to provide advice and support to patients with life limiting progressive illnesses up to and including end of life.

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DEFINITION OF ADVANCE CARE PLANNING

There are times in our lives when we think about the consequences of becoming seriously ill. Advance Care Planning (ACP) is the process of enabling a person to consider the impact of a future illness or disability and express wishes about their future health care in consultation with care providers and loved ones.

ACP is the process of discussing between you and those who are important to you, your views, wishes and preference about your future care so that these can be taken into account if you become unable to make your own decisions. You may wish to discuss your preferences with your partner, family, friends and those who are providing your care such as your care manager, nurse or doctor.

It can be helpful to think about:

- At this time in your life what makes you happy or feels important to you?
- What elements of care are important to you and what would you like to happen in the future
- What would you NOT want to happen? Is there anything that you worry about or fear happening?

These conversations should not just be 'one offs', will normally happen over a period of time and wishes and preferences may change as the individual become increasingly unwell.

It is important that the individual's wishes are shared across health care teams. The Urgent Care Plan (UCP) is an electronic system which enables people to share their wishes across health networks, including the 111 and London ambulance service. Urgent Care Plan for London :: North West London ICS (nwlondonics.nhs.uk)

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DEFINITION OF ADVANCE DIRECTIVE TO REFUSE TREATMENT

An ADRT is a legally binding document and as such has to be written in a certain way and witnessed. Unlike advance care plans which describe what you want to happen, ADRT is a directive to refuse a specific treatment at some time in the future. This could be because you might lose the ability to make or express your own decisions about treatment. It cannot be used to request specific treatments, if you wish to refuse life sustaining treatment it needs to be in writing, signed and witnessed and clearly state that you wish to refuse these treatments even if your life is at risk.

You must be over 18 and have capacity to make a ADRT.

Making decisions and wording an ADRT can be complex, and you may suggest the individual wanting to make an ADRT discuss this with their doctor. Please see Advance-Decisions-to-Refuse-Treatment-Guide.pdf (england.nhs.uk)

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SIGNS OF EOLC including few pointers to understanding that the service user is reaching end of life

Changes that you may see as someone reaches the last weeks or days of life. This process is unique to every single person. It is not always possible to know for sure that a person is in the last days of life or predict when a person will die or know exactly what changes the person you are caring for will experience when they are dying.

If an individual's condition gets worse unexpectedly or you think they may be reaching the last weeks of their life the person **must be seen by a doctor**. The doctor must judge whether anything can be done to improve the person's condition. If it can, and the person wants such attempts to be made, they must make sure that this is done quickly. If the doctor believes that the person will die soon, they must tell the person if appropriate and anyone else that the patient has said is important to them. This is likely to include other family members or friends.

Changes in the last days of life

- Reduced interest in the world
- Spending more time asleep – they are so drowsy that they only wake up when you talk or move them
- Being less able to their normal activities this may include – being able to wash themselves or walk around
- Reduced appetite- not feeling hungry or thirsty, not wanting to eat.
- Changes in breathing - their breathing pattern may change; they may breathe faster or there may be long gaps between breaths
- They may become restless of agitated
- Their skin colour may change – hands and feet may become cold to the touch, sometimes people's hand or feet may swell a little
- There will be changes to their urine and bowels, they may become incontinent, and their urine is likely to become very dark, they are likely to have less bowel movements.
- The persons eyes may be closed and not open when talking to you or may be half open all the time

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PEOPLE INVOLVED IN CARE

The GP will be able to refer any of these services

- **General practitioner**
- **Community/District Nurses** - Provide nursing care to patients at home with specific needs such as patients requiring wound care dressings, management of pressure areas etc. They also administer drugs that may be needed when people are no longer able to swallow such as pain medications. Physio and occupational therapists – they may be able to help with specialised equipment and aids to help with mobilisation
- **Formal carers**
- **Palliative care nurses** - Provide specific support and advice to anyone with a life limiting progressive illness, their relatives and carers. Palliative Care Teams also offer advice to other health professionals involved in the patients care and signpost to other services as required
- **Social workers** – they would only be involved if the person had specific needs
- **Marie Curie** –rapid response nurse, these nurses can visit over night between 9pm and 8 am, if the need support with symptoms.
- **Social prescribers** – they are based at the GP practice and can give advice and signpost people to other services
- **Counsellors**, they may be able to provide support for the individual and their carers, including bereavement support.
- **Support groups or workers** – e.g. carers support groups, welfare benefit advisors or advocates
- **Specialist healthcare** – learning disabilities or mental health

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DNACPR – Do not attempt Cardiopulmonary resuscitation

CPR stands for cardiopulmonary resuscitation. It is a treatment that can be given when you stop breathing (respiratory arrest) or your heart stops beating (cardiac arrest).CPR tries to get your breathing and heart going again.

CPR can involve:

- pressing down hard on your chest repeatedly (chest compressions)
- a machine to stimulate your heart using electrical shocks (sometimes more than once)
- equipment that helps move oxygen around your body (artificial ventilation)

CPR is a form of medical treatment and sadly is not always successful or in the persons best interests. Individuals can make the decisions not to be resuscitated as part of an advance directive.

DNACPR

DNACPR stands for do not attempt cardiopulmonary resuscitation. DNACPR is sometimes called DNAR (do not attempt resuscitation) or DNR (do not resuscitate) but they all refer to the same thing. This means that when the heart or breathing stops your healthcare team will not try to restart it. A DNACPR decision is made by individual and/or your doctor or healthcare team.

A DNACPR decision is usually recorded on a special form.. It may also be printed and kept in the home or in a care home. The individual and those important to them must be informed that a DNACPR form has been put in your medical records.

Who can decide?

Everyone who has capacity to do so can refuse CPR if they wish. This is a choice you can make at any time, for example when you are healthy or when you are approaching the end of your life. You cannot choose to be resuscitated

However DNACPR is a medical treatment decision that can be made by your doctor even if you do not agree.You must be told that a DNACPR form will be/has been completed for you, but a doctor does not need your consent. Doctors can only not tell you that a DNACPR form has been completed for you if they think doing so would cause you physical or psychological harm
Important DNACPR is about CPR only and does not stop the invidual having all other care including antibiotics and fluids

For more information see

Do not attempt cardiopulmonary resuscitation (DNACPR) decisions - NHS (www.nhs.uk)

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CASE STUDIES

Case Study 1:

Rose, 57, cares for her husband, Karl, who has terminal cancer. She also has a son who is autistic.

"We have suffered for so many years. We lived in a one room flat for many years where my son and I would have to take turns sleeping on the floor. The flat had mould and mildew which would make us cough and get sick. Last Christmas, the flat flooded with sewage ruining many of our things.

I had to be strong for my husband. I didn't want him to die in that place. It was so hard though and there was never laughter in our house.

We just about made ends meet with me doing some shift work and my husband's pension although we couldn't afford to buy a cooker. My husband needs a special diet to help keep him strength up and I felt so anxious and depressed that I couldn't give him that.

My GP saw how much I was struggling and helped us get a social services assessment and we were finally rehoused in January this year to a two-bedroom flat. I was also introduced to Peter at Carers First. He helped me secure the Carers Allowance, filling in the forms for me. He also got me a grant for a new cooker.

Life is so much better now. My son and I no longer must take turns sleeping on the floor. I use the Carers Allowance to buy better food which I can cook with my new cooker. I feel so glad that I can take better care of my husband.

We are all happier and there is laughter in our house again.

I am so grateful for what Peter and Carers First have done for my family. I recommend Carers First to everyone, telling my story about the change they have made in my life. In the summer I have promised to meet up with other carers and cook for them. Life now feels more hopeful."

Case Study 2:

Mrs Smith was an 85-year-old woman. She was diagnosed with myeloma whilst in hospital where she was admitted for pneumonia. She was identified as someone quite frail and high risk using the early identification search tool. Mrs Smith along with her nephew were invited for discussion around advance care planning. The GP posted the advance care plan questions before the discussion. After discussion with her nephew, Mrs Smith chose not to be resuscitated. The advance care plan was completed by the GP and signed. This allowed access to her care plan for healthcare professionals.

A few months later Mrs Smith was diagnosed with pancreatic cancer. Her care plan was updated, and she was looked after by the GP and palliative care team at home. A few weeks later from the diagnosis Mrs Smith peacefully died at home with her nephew present.

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RESOURCES - 1

E learning
End of life care for all e-ELCA_programme_catalogue_120821-1.pdf (e-lfh.org.uk)
The my CMC site has a very good videos which explain what a care plan is, it also has information about DNACPR and treatment options. To see them you have to log as ask if you were creating a care plan MyCMC | Coordinate My Care | Urgent Care Plan

Significant 7 Tool
Significant Care – Significant 7 Tool

Comprehensive tool Kit including information on ACP, Bereavement Finance and sources of information and help End of life care - Newham's vision – End of life care – Newham Council

Care planning
Advance care planning in 5 Simple steps – Hospice Uk https://vimeo.com/216198924
Planning ahead: My treatment and care Planning Ahead: My treatment and care | Compassion in Dying
Planning ahead Your treatment and care for the LGBT community. Planning ahead for the LGBT community | Compassion in Dying
Planning ahead: a checklist of what you may want to consider. Planning ahead | Dying Matters
Planning ahead: Thinking about your care and wishes ahead of time. planning-ahead.pdf This leaflet give provides a guide to everything that needs to be considered from thinking about where you want to be cared for
My future wishes Advance Care Planning (ACP) for people with dementia in all care setting my-future-wishes-advance-care-planning-for-people-with-dementia.pdf (england.nhs.uk)
Thinking ahead Gold Standards Framework Thinking Ahead (3).pdf (gsfcentre.co.uk)
Urgent Care Plan- Urgent Care Plan for London :: North West London ICS (nwlondonics.nhs.uk)
Urgent Care Plan patient leaflet -Leaflet_FIN_Print (nwlondonics.nhs.uk)
Urgent Care Plan patient leaflet (web version) Urgent-Care-Plan-Patient-Leaflet-Web.pdf (nwlondonics.nhs.uk)

ADRT
Advance Decisions (living will) Advance decision (living will) - NHS (www.nhs.uk)
My decisions; A free simple website this has form that people can complete Welcome – My Decisions
How to make an advance decision (this has a template form) How to make an advance decision | Alzheimer's Society (alzheimers.org.uk)

DNACPR
Your guide to decisions about Cardiopulmonary resuscitation (CPR) Your guide to decisions about cardiopulmonary resuscitation (CPR) (dyingmatters.org)

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RESOURCES - 2

Caring for dying person
What to expect at someone end of life this booklet by Marie Curie gives information on who might be involved in the persons care and what to expect as someone starts to die, it also talks about what to do at the time of death and a little about early bereavement **.** What to expect at the end of someone's life (mariecurie.org.uk)

It helps to talk – Skills for Care - Although fictitious, this film is based on the experiences of people that we spoke to at a series of workshops which were held about end of life care. It is an emotional film about a motor neurone disease sufferer who conveys her end of life wishes to her son and sister, and shows how the lack of communication between front line workers can cause unnecessary stress and upset to everyone involved.
Please be aware that this is a story about the end of someone's life and may be distressing for some people.
https://vimeo.com/109108248

Supporting someone at the end of their life
Supporting someone who may be approaching the end of their life can be some of the most challenging work that any social care or health worker faces. https://www.skillsforcare.org.uk/Learning-development/ongoing-learning-and-development/end-of-life-care/End-of-life-care.aspx

Understanding Roles: a booklet and videos about the different roles that might be involved in providing end of life care for someone.
Booklet: Working together to improve end of life care
Video: Overview film of all roles

What to do when someone dies/ Bereavement

When someone dies – this booklet by Marie Curie provides an overview of the practical and emotional issues that you may face when someone close to you dies. Including what to do when the death occurs, verifying and certifying the death, registering the death and planning a funeral. Legal issues and coping with grief and supporting those around you, including children. When someone dies (mariecurie.org.uk)
What to do when someone dies - what should I do next? | Age UK
What to do after someone dies - GOV.UK (www.gov.uk)

The bereavement advice centre has good information a wide range of topics including what to do when someone dies, registering the death and who to inform and what to expect in bereavement. Bereavement Advice Centre | Topics | Helpful Information
Coping with Grief 06652 - Coping with Grief A5 Booklet v12 DIGITAL.pdf
Easy read – Feelings you may have when someone dies Easy Read: Feelings when someone dies (mariecurie.org.uk)

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RESOURCES - 3

DNACPR

DNACPR-Patient-Info-leaflet-v2.pdf (tvscn.nhs.uk)
Your guide to decisions about cardiopulmonary resuscitation (CPR) (dyingmatters.org)
Respect Easy read ReSPECT easy-read leaflet 1 - Introduction(1).pdf (uhcw.nhs.uk)

End of life

What to expect in the last days of life
Medicines in the last days of life
Your 'Just in Case' Medication
Referral Criteria

What to do when someone dies

E learning
End of life care for all e-ELCA_programme_catalogue_120821-1.pdf (e-lfh.org.uk)