

## Directorate of Palliative Care

### The Role of the Palliative Care Network Nurse.

*“Focusing on End of Life Care.”*



March 2010

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***“How we care for the dying is an indicator of how we care for all sick and vulnerable people.”***

End of Life Care Strategy

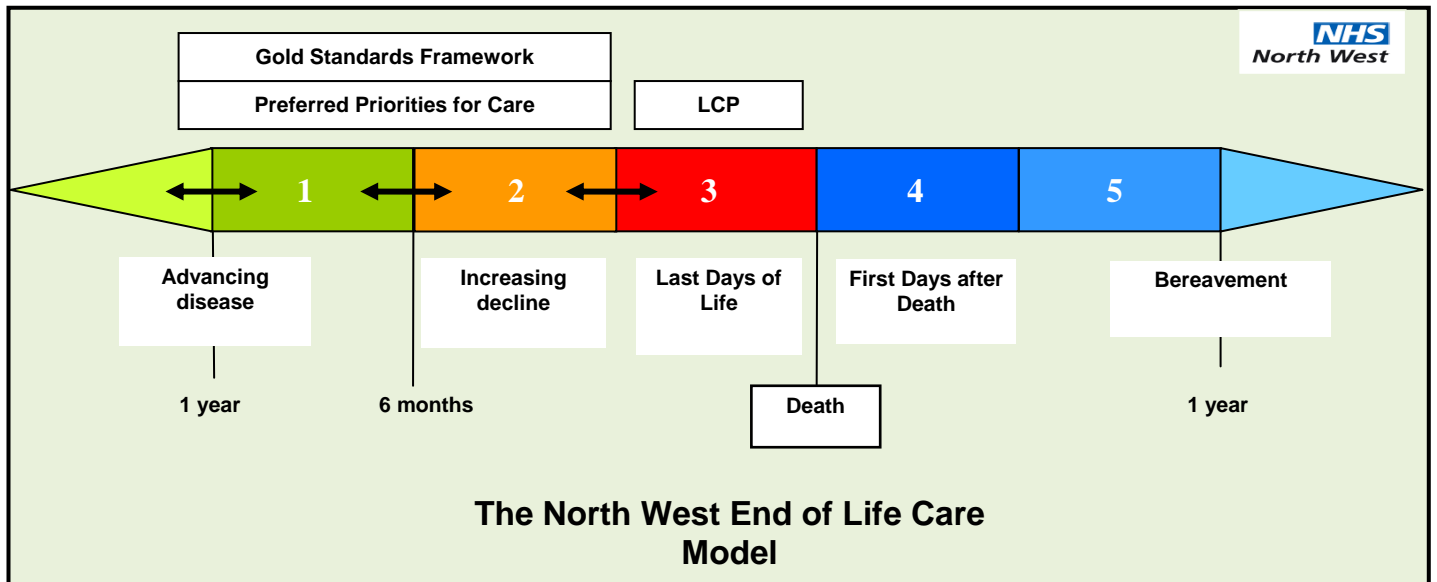
Promoting high quality care for all adults at the end of life.

(Department of Health, London. 2008)

## What is End of Life Care?

End of life care is the active and compassionate approach to care, for all people with progressive, advanced, irreversible conditions, estimated to be in the last months/year of life.

Good end of life care enables people to live well and die well in the place of their choosing and is one of the fundamental rights of each person.



## The North West End of Life Care Model

This model comprises five phases as described below with some examples of practice highlighted;

**Advancing disease** – time frame -1 year or more. Example of practice required -the person is placed on a Supportive Care Register in General Practitioner (GP) Practice or Care Home. The person is discussed at monthly multidisciplinary GP Practice/Care Home meetings.

**Increasing decline** – time frame - 6 months [approximate]. Example of practice required, DS1500 eligibility review of benefits, Preferred Priorities for Care (PPC) noted, Advance Care Plan (ACP) in place and trigger for Continuing Healthcare Funding assessment.

**Last days of life** – time frame - last few days. Examples of practice required - Primary Care Team/Care Home inform community and out of hours services about the person who should be seen by a Doctor. End of life drugs prescribed and obtained, and Liverpool Care Pathway (LCP) implemented

**First days after death** – time frame - first few days. Examples of practice required include prompt verification and certification of death, relatives being given information on what to do after a death (including D49 leaflet), how to register the death and how to contact Funeral Directors

**Bereavement** – timeframe -1 year or more. Examples of practice required include access to appropriate support and bereavement services if required

## The Palliative Care Network Nurse Programme

The Palliative Care Network Nurse Programme was developed to educate and skill generalist nurses in the care of the dying patient, within the acute hospital setting. It developed at the request of nurses who had been involved in the piloting of the Liverpool Care Pathway for the Dying Patient and has been operational since 1999. There are now over 80 Network Nurses in this Trust.

Palliative Care Network Nurses act as a resource to the Clinical Teams in which they work. Their key role is to support their colleagues, assist the Hospital Specialist Palliative Care Team (HSPCT) with palliative care and end of life care education within their clinical areas and to promote and support the use of the recognised end-of-life tools.

## What are the benefits of being a Palliative Care Network Nurse?

The End of Life Care Strategy (Department of Health, 2008) recognised that the delivery of high quality end of life care to individuals, their families and carers requires nothing less than a cultural shift in attitude and behaviour within the health and social care workforce.

As a Palliative Care Network Nurse you will play a pivotal part in this cultural shift within the Royal Liverpool and Broadgreen University Hospitals NHS Trust. By leading the way in end of life care in your own ward area, your innovative work will directly benefit patients and their relatives and carers and will translate into immense personal and professional job satisfaction.

You will have the opportunity to identify specific individual learning objectives and liaise regularly with your nominated Macmillan Palliative Care Nurse Specialist Mentor. You will spend a one day placement each year working directly with your Mentor and with the HSPCT.

This direct support will help you to address your own personal and professional development and consolidate your existing skills in the four key areas of end of life care as outlined by the Department of Health in 2009:

- *Communication Skills*
- *Assessment and Care Planning*
- *Symptom Management, Comfort and Wellbeing*
- *Advanced Care Planning*

You will be supported by the HSPCT to cascade and share your knowledge in end of life care to your colleagues in your ward or area.

### **In addition;**

- Four (fully funded) Study Days will be offered throughout the year in conjunction with the Palliative Care Network Nurses from Primary Care. The topics for each study day are chosen by the combined group of community and acute hospitals Network Nurses. You will be expected to attend at least 2 of these study days per year. The Venue for these study days will always be The Marie Curie Palliative Care Institute Liverpool at the Marie Curie Hospice (in Woolton), unless otherwise specified.
- You will have access to the Network Nurse Shadowing Programme with colleagues from Primary Care and Hospice. Each year, the shadowing programme involves 3 nominated nurses from RLBHUHT, Community and Marie Curie Hospice spending a 2-day placement in each other's care setting to enable them to have an increased understanding of the strengths and challenges of providing care across different settings.
- You may have access to funds for palliative care education at Diploma, Degree and Masters level.
- You will receive a Network Nurse Certificate for your Personal Professional Portfolio.
- You will have an opportunity to be part of a wider network of generic Nurses who demonstrate an interest in end of life care across the health economy.

## The Role of a Network Nurse

### As a Palliative Care Network Nurse you will;

- Be expected to take a lead role in the support and management of patients with palliative care and end of life issues on your ward. The HSPCT will support you to develop competencies and empower you to be able to share knowledge and skills pertaining to end of life care with other generic workers in your ward environment.
- Be expected to take responsibility for and recognise the importance of your own continuing professional development.
- Be aware of any patients who have been referred to the HSPCT and ensure that all referrals are appropriate. You should also ensure that staff are aware that the Medical Team should document their agreement for referral to the HSPCT in the patients medical notes.
- Ensure that you monitor the care of any patient who is being cared for on the Liverpool Care Pathway for the Dying Patient (LCP) on your ward or area, even if this patient is not within your group of patients for that shift. This should include ensuring that all parts of the LCP are completed appropriately, any variances are clearly documented and there is no missing data on the LCP. All LCP's are subject to regular Audit, both locally and nationally.
- Be the key worker for the Continuous Quality Improvement Framework on your ward and should ensure that you and your colleagues are aware of the relevant sections pertaining to end of life care on the Nursing Quality Performance Assessment Tool.
- Ensure that colleagues on your ward know where to access the LCP documents and supporting leaflets. You will take responsibility for regularly checking and organising replenishment of the stock items from LCP blue box file.
- Be expected to demonstrate that you have taken opportunities to raise awareness and carried out formal or informal teaching opportunities regarding end of life care with your colleagues; either on a 1:1 basis or in small groups. You will be expected to record any teaching carried out on your Education Personal Record Sheet (even if this has been a 5 minute session with one colleague, based on one goal of the LCP). These record sheets will be collated at the end of each year by the HSPCT Lecturer Practitioner to monitor how this 'cascade model' of end of life care education is working.
- Be expected to take a lead role in educating ward colleagues regarding the safe use of the Graseby MS26 syringe driver (CSCI).
- Be expected to identify any difficulties or any additional support you need to carry out your ward based education to your Line Manager and to your nominated Macmillan Palliative Care Nurse Specialist Mentor at the earliest opportunity.
- In association with your Line Manager, you should be able to identify any staff from your area who would benefit from attending the (one day) HSPCT Foundation Day training in End of Life Care. You should ensure that they contact the HSPCT Lecturer Practitioner to allocate a date for this training.

**An end of life care resource folder containing supportive information will be available to you and your colleagues on the ward. A copy of the Merseyside and Cheshire Palliative Care Network Audit Group - Standards and Guidelines will be available to you and your colleagues within your clinical area. It will be your responsibility to ensure that this is kept in a safe place, in a good condition and that you inform the HSPCT of any lost or damaged copies.**

## **Palliative Care**

Palliative care is;

*“The active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.”*

(World Health Organisation. National Cancer Control Programmes: Policies and guidelines. Geneva: 2002)

## **Specialist Palliative Care**

Specialist palliative care is provided

*“... by a multi-professional team who have undergone recognised specialist palliative care training... and will involve practitioners with a broad mix of skills, including medical, and nursing, social work, pastoral/spiritual care, physiotherapy, occupational therapy, pharmacy and related specialities.”* (National Council for Hospice and Specialist Palliative Care Services, 2000)

Palliative care is provided by two distinct categories of health and social care professionals: Those providing the day-to-day care to patients and carers in their homes and in hospitals and those who specialise in palliative care (Consultants in Palliative Medicine and Clinical Nurse Specialists in Palliative Care).

Those providing day-to-day care should be able to:

- Assess the care needs of each patient and their families across the domains of physical, psychological, social, spiritual and information needs
- Meet those needs within the limits of their knowledge, skills, and competence in palliative care
- Know when to seek advice from or refer to specialist palliative care services

## **The role of the Hospital Specialist Palliative Care Team (HSPCT)**

The Directorate of Specialist Palliative Care encompasses the Hospital Specialist Palliative Care Team, the Complementary Therapy Service and a Satellite Unit of The Marie Curie Palliative Care Institute Liverpool (MCPCIL) and offers a resource to Hospital staff for information on quality of life issues for all those with advanced incurable disease irrespective of diagnosis.

## **Philosophy of the HSPCT**

To provide specialist palliative care for patients and carers, by advising on pain and symptom control, facilitating spiritual and social support and providing psychological and bereavement care. To empower health professionals to provide evidence based palliative care through education, research and audit. To collaborate with health providers across settings to promote national and local policies in pursuit of a seamless palliative care service.

## **Referral criteria for HSPCT**

Access to the HSPCT can be gained for both inpatients and outpatients.

## Reasons for referral

1. Pain
2. Other Symptoms – e.g. Nausea
3. Psychological support for the patient/family
4. Patient dying with distressing symptoms
5. Problems regarding insight of the patient/family
6. Advice regarding complex placement.

## How to refer

There is a requirement to;

- Obtain the treating Clinical Team's agreement to refer to the HSPCT.
- Include a written referral in the patients case notes by the treating Clinical Team
- A referral via the Hospital Information Computer System (ICE) for inpatients or patients attending other out patient clinics
- A referral letter addressed to Dr Laura Chapman (Consultant in Palliative Medicine) for a request to our Specialist Out Patient Clinic.

## Immediate information and support for any patient:

- Bleep **4191**
- Telephone ext. **2274**
- **7 days** per week **9am – 5pm**
- For Health Professionals who require advice between 5pm and 9am;  
**Out of hours Specialist Palliative Care Advice Line 0845 223 2900**

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Care Institute Liverpool (MCPCIL)  
Lead Nurse – LCP  
Deborah Murphy**

**Professor of Palliative Medicine  
Director of Marie Curie Palliative Care  
Institute Liverpool (MCPCIL)  
Clinical Lead – LCP  
John Ellershaw FRCP**

**Consultant  
Dr. Laura Chapman**

**Office Manager  
Debbie Griffiths**

**Macmillan Palliative Care Nurse Specialists  
Phil Saltmarsh (Assistant Directorate Manager)  
Anne Black  
Helen Ferguson  
Jenny Carlson  
Lynne Cannell  
Malcolm Cooper  
Michelle O'Connor  
Rita Doyle**

**Complementary Therapists  
Pam Shepherd  
Bernie Fletcher**

**LCP Facilitator  
Maria Bolger**

**Specialist Social Worker  
Janet Roberts**

**Specialist Registrar and Senior House Officer  
(Rotational posts)**

## End of life care

Currently, 58% of all deaths occur in NHS hospitals. The aim of high quality end of life care in hospital is to ensure that;

- Where possible, people are able to discuss and identify their own preferences and priorities around end of life care. These should be documented, reviewed, respected and acted upon wherever possible.
- People are treated with dignity and respect at the end of their lives.
- Pain and suffering are kept to an absolute minimum with access to skilful symptom management for optimum quality of life.
- The services needed are well co-ordinated so that the patient receives seamless care.
- High quality care is provided in the last hours or days of life and after death .
- Carers are appropriately supported both during a persons life and into bereavement.
- Health and social care professionals at all levels are provided with the necessary education and training to enable them to provide high quality care.

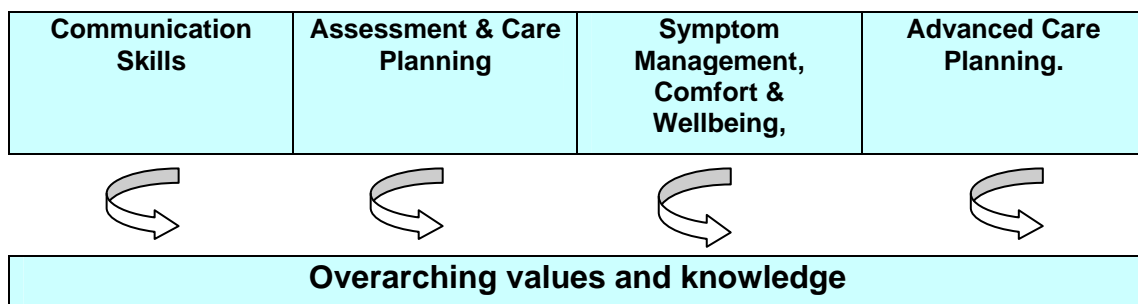
At the end of life, all care and support should centre around the needs, wishes and priorities of the individual receiving the care. As people approach the end of their life these may change and take on a different perspective. When this occurs healthcare professionals need to be able to adapt their current practice to take account of this.

Patterns of care should alter to accommodate a shift from cure, increasing independence and future planning to managing symptoms and concerns and ensuring that the individual and their family and friends are able to spend time in a way that is meaningful to them and is as positive as possible.

Four key areas have emerged to address workforce development and improve competence in end of life care;-

- *Communication skills,*
- *Assessment and Care Planning,*
- *Symptom Management, Comfort and Wellbeing*
- *Advanced Care Planning.*

These four key areas should be supported by overarching values and knowledge in end of life care.



# Required Competencies for Healthcare Professionals in End of Life Care

## Communication Skills

Recognize that a patient's priorities and ability to communicate may vary over time.

- Communicate with a range of people on end of life care matters
- Listen to individuals, their families and friends about their concerns related to end of life care.
- Provide information and support
- Work with individuals, their families and friends demonstrating awareness of the impact of death, dying, bereavement.

## Assessment and Care Planning

Regularly review assessments taking account of changing needs, priorities and wishes.

- Understand the range of assessment tools
- Assess pain and other symptoms
- Ensure all assessments are holistic including;
  - Background information
  - Current physical health
  - Insight and prognosis
  - Social/occupational well-being
  - Psychological and emotional well-being
  - Spiritual and/or religious well-being
  - Culture and lifestyle goals and priorities
  - Risk
  - The needs of families and friends, including carer's assessment

## Symptom management comfort and well being

Symptom management at the end of life

- Be aware that symptoms have many causes including the disease itself, it's treatment, a concurrent disorder, including anxiety or depression or other psychological or practical issues.
- Understand the significance of the individual's own perception of their symptoms to any intervention
- Understand the range of therapeutic options available.
- In partnership with the individual, their family and friends develop an end of life care plan.
- Knowledge of the use of the end of life care Tools including the Liverpool Care Pathway for the Dying Patient (LCP).

## Advance Care Planning

Work sensitively with families and friends to support them as the individual decides upon their wishes and preferences.

- Demonstrate awareness and understanding of Advance Care Planning and the times at which it would be appropriate
- Demonstrate awareness of the legal implications of Advance Care Planning in accordance with the provisions of the Mental Capacity Act 2005
- Show understanding of informed consent and demonstrate ability to give sufficient information in an appropriate manner.
- Use effective communication skills when having discussions as part of ongoing assessment and intervention

## These four key areas should be supported by overarching values and knowledge in end of life care

- In the context of end of life care, understanding and knowledge of:
  - One's own professional boundaries
  - Legal and ethical issues
  - Professional codes of practice or conduct
  - The role/contribution of other workers and organisations
  - The impact of one's own beliefs on practice
  - Approaches to risk assessment and management
  - Approaches to and theories of change, loss and bereavement
  - Social models of care and person-centred approaches
  
- Person-centred practice that recognises circumstances, concerns, beliefs, and cultures of the individual
- Acknowledges the significance of spiritual, emotional, and religious support and diversities.
- Practice that is sensitive to the support needs of family and friends, including children and young people as part of end of life care and following bereavement
- Awareness of the importance of contributing to evaluation and change of services.

Taking responsibility for one's own learning and continuing professional development and contributing to the learning of others.

***“Common core competencies and principles for health and social care workers working with adults at the end of life”*** (Department of Health, Skills for Care, Skills for Health, National End of Life Care Programme, 2009)

As a Palliative Care Network Nurse you will be supporting your colleagues in your ward or area to develop their own competencies in end of life care.

**N**urses can make a difference  
**E**ducation increases confidence  
**T**ime well spent  
**W**orking to improve patient care  
**O**pportunity for dissemination  
**R**aising the profile of palliative care  
**K**nowledge leads to empowerment

## The Liverpool Care Pathway for the Dying Patient (LCP)

Over the past few years a major drive has been underway to ensure that all dying patients, and their relatives and carers receive a high standard of care in the last hours or days of their life. The Liverpool Care Pathway for the Dying Patient (LCP) within the LCP continuous quality improvement programme was designed at the Marie Curie Hospice Liverpool and RLBUHT in the late 1990's and is one of the key programmes within the Marie Curie Palliative Care Institute Liverpool (MCPCIL) portfolio. A satellite unit of the Institute is based within the Directorate of Palliative Care at this Trust.

The LCP was recognised in England as a model of best practice in the NHS Beacon Programme (2001). It was then subsequently incorporated into the Cancer Services Collaborative Project and the National End of Life Care Programme (2004 -7). It was recommended in the NICE guidance on supportive and palliative care for patients with cancer (2004), as a mechanism for identifying and addressing the needs of dying patients. It was recommended in the Our Health, Our Care, Our Say White Paper 2006, as a tool that should be rolled out across the country. It is recommended in the End of Life Care Strategy DH (2008) and highlighted in the Department of Health End of Life Care Quality Markers document (2009).

<b>The LCP Continuous Quality Improvement Programme incorporates:</b>	
<p><b>1. Aim</b> To improve care of the dying in the last hours or days of life</p> <p><b>2. Key Themes</b> To improve the knowledge related to the process of dying To improve the quality of care in the last hours or days of life</p> <p><b>3. Key Sections</b> Initial Assessment Ongoing Assessment Care after death</p>	<p><b>Key Domains of Care</b></p> <p>Physical Psychological Social Spiritual</p> <p><b>5 Key Requirements for Organisational Governance</b></p> <p>Clinical Decision Making Management &amp; Leadership Learning &amp; Teaching Research &amp; Development Governance &amp; Risk</p>

## LCP generic version 12– consultation exercise

Following a 2 year consultation exercise including the latest evidence from 2 rounds of the National Care of the Dying Audit - Hospitals (NCDAH), LCP generic version 12 - UK was published in December 2009

The ethos of the LCP generic document has remained unchanged - LCP generic version 12 – UK has greater clarity in key areas, particularly communication, nutrition and hydration. Care of the dying patient and their relative or carer can be supported effectively by either version of the LCP. The responsibility for the use of the LCP generic document as part of a continuous quality improvement programme sits within the governance of an organization underpinned by a robust ongoing education and training programme.

## Key Messages for the Healthcare Professional using the LCP generic version 12 - UK

The LCP is only as good as the Team who use it, and its use must be underpinned by a robust ongoing education and training programme. As with all clinical guidelines and pathways, the LCP aims to support but does not replace clinical judgement.

### **10 KEY LCP Messages**

- 1. The LCP is only as good as the people who are using it**
- 2. The LCP should not be used without the support of education and training**
- 3. Good communication is pivotal to success**
- 4. The LCP neither hastens nor postpones death**
- 5. Diagnosis of dying should be made by the multidisciplinary team (MDT)**
- 6. The LCP does not recommend the use of continuous deep sedation**
- 7. The LCP does not preclude the use of artificial hydration**
- 8. The LCP supports continual reassessment**
- 9. Reflect, Audit, Measure & Learn**
- 10. Stop, Think, Assess & Change**

***The responsibility for the use of the LCP generic version 12 - UK document as part of a continuous quality improvement programme sits within the governance of an organisation and must be underpinned by a robust education and training programme***

***As a Palliative Care Network Nurse you should ensure that you monitor the care of all patients whose care is being supported by the LCP on your ward.***

***You have a pivotal role to play in driving up the quality of care of any patient who is in the last hours or days of life within your ward or area.***

## LIVERPOOL CARE PATHWAY FOR THE DYING PATIENT (LCP) LCP HELPFUL REFERENCES

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4. Spiritual and Religious Care Competencies for Specialist Palliative Care:  
Assessment Tools level 1&2  
Self-assessment tools levels 3&4  
David Mitchell & Tom Gordon  
Marie Curie Cancer Care - [www.mariecurie.org.uk/healthcare](http://www.mariecurie.org.uk/healthcare)

## OTHER USEFUL WEBSITES

Marie Curie Palliative Care Institute Liverpool

[www.mcpcil.org.uk](http://www.mcpcil.org.uk)

Marie Curie Cancer Care

[www.mariecurie.org.uk](http://www.mariecurie.org.uk)

End of Life Care Programme

'Making Change Happen'

[www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

National Council for Palliative Care

[www.ncpc.org.uk](http://www.ncpc.org.uk)

National Confidential Enquiry into Patient Outcomes and Death (NCEPOD)

[www.ncepod.org.uk](http://www.ncepod.org.uk)

Mental Capacity Act Code of practice:

[http://www.opsi.gov.uk/acts/acts2005/related/ukpgacop\\_20050009\\_en.pdf](http://www.opsi.gov.uk/acts/acts2005/related/ukpgacop_20050009_en.pdf)

Decision relating to Cardiopulmonary Resuscitation:

<http://www.bma.org.uk/ap.nsf/Content/CPRDecisions07>

The Decision to withdraw Implantable Cardioverter Defibrillator (ICD) Therapy in an Adult Patient:

<http://www.cmcn.nhs.uk/guidelines/icds.html>

E-Learning for Healthcare

<http://www.e-lfh.org.uk/index.html>

**'The Role of the Palliative Care Network Nurse'**

revised March 2010

for review March 2012

Rita Doyle – Macmillan Palliative Care Nurse Specialist / Lecturer Practitioner

**If you have any queries please contact:**

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