REPORT TO: Health & Wellbeing Board

DATE: 18th September 2013

REPORTING OFFICER: Strategic Director, Communities

PORTFOLIO: Health and Adults

SUBJECT: End of Life Services

WARD(S) Borough-wide

1.0 PURPOSE OF THE REPORT

1.1 To provide an overview of current End of Life services available in Halton including future priorities.

2.0 RECOMMENDATION: That the Board note and comment on the content of the report and the attached Appendix.

3.0 SUPPORTING INFORMATION

3.1 National Context

The End of Life Care Strategy: Promoting High Quality Care for all Adults at the End of Life was produced by the Department of Health in 2008. The strategy outlines the 6 key elements of the end of life pathway:

- Step 1 Discussions as the end of life approaches;
- Step 2 Assessment, care planning and review;
- Step 3 Coordination of care for individual patients;
- Step 4 Delivery of high quality services in different settings;
- Step 5 Care in the last days of life; and
- Step 6 Care after death.

In addition the pathway should be supported by the use of well-established end of life tools and a robust clinical support network, comprising of GP's, District Nurses, Consultants in Palliative Care, Speciality Doctors, Macmillan Nurses and Macmillan services and care, support and bereavement services.

4.0 Local Approach

The Model of support in Halton consists of a range of services and systems of support to ensure that the requirements of the patient pathway are met along with the support networks within the community (Appendix 1 Model of provision).

4.1 Identifying a Patient Approaching End of Life

Identifying when a patient is approaching the end stages of life is inherently difficult. As such, within primary care it is necessary to

ensure that there is guidance in place to assist in identifying those patients and ensure they are recorded and monitored so that their care can be effectively coordinated.

The Gold Standard Framework (GSF) is a system designed to support this process supported by GSF Prognostic Indicator Guidance. This guidance is to assist GP's in identifying symptoms that would indicate a patient is approaching the last 12 months of life. Once this identification has been made they should then be added to an End of Life register within their GP Practice.

By adding a patient to an End of Life register, this will allow regular multi-disciplinary discussions to take place to discuss that patients care. These discussions will ensure clarification of patient needs, the ability to provide pro-active support and act as a mechanism to prompt advanced care planning discussions.

The aim in Halton is for all GP's to adopt GSF principles in order to provide seamless care at end of life. To facilitate this, a Cancer and End of Life forum with a representative from each GP practice in Halton has been established to identify any gaps and provide an opportunity to share best practice.

4.2 <u>Advanced Care Planning</u>

Evidence suggests that most people, if given the choice would prefer to die at home. If a patient has been identified as approaching the end of life it is necessary for the team caring for the patient to initiate discussions to establish what the patient wishes are in relation to their care.

In order for this to happen, we need to ensure that staff and healthcare professionals feel comfortable in initiating these conversations with patients and families and feel confident in explaining the decisions that can be put in place to ensure patient wishes are adhered to.

To facilitate this, an Advanced Care Planning Team has been established within Halton, which includes an End of Life Care Facilitator and a Project Support Officer who are supported by the wider Palliative care network. The role of the Advanced Care Planning team is to provide staff within both health and social care settings with the skills and training to be able to initiate discussions and effectively communicate with patients and families.

To date, a number of initiatives have taken place to improve end of life skills across health and social care including;

- Bespoke training with GP Practices including all staff.
- Half day training events on end of life tools
- Commencement of the Six Steps training programme in 11 Care Homes

- A two day training Course across care management and assessment services with the aim of increasing knowledge of end of life care issues, which was attended by 74 staff including managers, Social workers, Occupational Therapists and Community Care Workers.
- A number of end of life champions identified across social care teams who will attend a Multi-Agency End of Life Champions Forum.

4.3 24/7 Palliative Care Advice Line

Following a recommendation in Dying Well at Home: The Case for Integrated Working and to further support staff in feeling confident to make decisions regarding end of life care, a 24-hour Palliative Care Advice Line Service was implemented in Halton in October 2012, open to all health and social care professionals across Halton. It is staffed by experienced Palliative Care health professionals working in community, hospice and hospital environments who are able to assist staff in making appropriate decisions at the end of life.

To date, the advice line has provided guidance to GP's, District Nurses, Hospital staff and nursing home staff and will continue to act as a palliative care resource. Evaluation and feedback of the service is carried out monthly and the feedback suggests that this is a valuable service in providing confidence to health professionals in making the right decisions at the end of life. One comment stated:

'Particularly at weekends and evenings you can feel isolated when it comes to being unsure of the course of action to take. I felt very relieved that I had an expert to discuss the situation with so I was able to give the correct care / medication with confidence.'

4.4 <u>Choices Available to Patients at End of Life</u>

Once discussions have been initiated with a patient it may become clear that a patient has specific wishes regarding their treatment at the end of life. For example, this could be to remain at home or be cared for within a hospice environment or they may wish to avoid certain interventions if their condition worsens.

As such there are services and documentation that can be put in place to alert all staff involved in their care to these decisions and preferences and ensure that their patient's wishes are clear.

4.5 <u>Supporting patients in the community</u>

There are a range of services available in the community if a patient wishes to be cared for within their home

End of Life Care Service

This service is provided by Halton Borough Council and supports the work of the District Nurses in the community. The service is available 24 hours a day. The service cared for a total of 143 patients in 2011/2012.

Palliative Care Sitting Service
To support carers who may be in the position in which they are the main carer for a relative there is also a palliative care sitting service available.

Macmillan Nursing Team
This is a team of Clinical Nurse Specialists, which operates 7 days a week providing specialist advice, support and education.

Halton Haven Hospice
Halton Haven Hospice provides 12 inpatient beds along with day hospice and outpatient services. The hospice is staffed by Specialists in Palliative Care including a Consultant in Palliative Care Medicine therefore providing expert medical care for those with complex symptoms and for those patients who may prefer to be within a hospice environment. Admissions are generally for people who require further medical care to manage complex symptoms.

Halton Haven Hospice also provides a Family Support Service which is available to both patients and families within the service and can also be accessed following bereavement. The service provided support to approx. 400 individuals in 2011/12, and it is estimated that this service also indirectly benefits many more family members.

2013/14 will see the expansion of the Family Support Service into a new purpose-built facility providing extra capacity along with dedicated 'Men's Shed' area to provide support for the male population in an environment that is tailored to their needs.

Nursing Homes
There are a number of patients who are cared for in nursing homes at the end of their lives. It is important for nursing home staff to be provided with the necessary skills to have end of life discussions and to document patient's wishes which is a key priority for Halton over the next 12 months. To date, a total of 11 care homes have begun a Six Steps training programme which covers the six key elements of the patients' pathway and also provides training on communication skills.

Hospital Palliative Care Services
Avoiding unnecessary hospital admissions is a priority for the CCG and a hospital admission is something which evidence suggests patients would also like to avoid where possible however if necessary both St Helens and Knowsley Trust and Warrington and Halton Hospital Foundation Trust provide a Specialist Palliative Care Service with Consultants in Palliative Care and supporting doctors, nurses and health care assistants should hospital care be needed.

4.6 <u>Decisions Regarding Treatment</u>
In addition to the services and facilities available, there are a number

of decisions that can be made regarding treatment and supporting documentation put in place to record those decisions. These decisions would be made through open discussions and clear communication with patients and families by health professionals who feel confident in their use via the training provided through the Advanced Care Planning Team and the End of Life Facilitator. All decisions would be signed by the most Senior health care professional either the GP or a hospital consultant. The appropriate use of these tools is reliant on open and honest conversations with patients and families.

These could include:

Preferred Priorities of Care This document is produced by the National End of Life Care Programme and is designed to help people prepare for the future, giving them the opportunity to talk about and write down their preferences and priorities for their care, for example their preferred place of care. This was implemented via the Advanced Care Planning Team in 2010 and will continue to be part of the training programmes offered to health and social care staff.

Advance Decisions to Refuse Treatment (ADRT)
An ADRT is a legally binding document that can be put in place to document treatment which the patient does not wish to receive in advance. For example if a patient, due to their illness was likely to lose capacity at a later stage, they may wish to specify the treatment they do not wish to receive, for example they may not wish to have invasive surgery. This was made legal in October 2007 and is discussed as part of the end of life tools training provided by the Advanced Care Planning Team

Do not attempt Cardio Pulmonary Resuscitation (DNACPR)
A DNACPR order is used when a patient does not wish to be resuscitated should their heart stop. Unlike an ADRT this is not a legally binding document and this decision may also be made based on a person's likelihood of survival following a resuscitation attempt.

Within Halton, along with the rest of the North West, there is now a regional DNACPR document being implemented this will ensure that wherever a patient is being treated within the healthcare system, the form is recognised and resuscitation is only carried out for those patients who wish to receive it or for whom it is clinically beneficial

Best Interest Decisions It may be necessary in certain circumstances, for example if a patient lacks capacity, following a review by the healthcare team, that decisions need to be made in the best interest of patients. These decisions would be made by senior healthcare professionals, in collaboration with families or named advocates where possible based on the patient's condition and the likely outcome of any interventions.

For example, resuscitation attempts have a poor success rate and can often leave patients with severe injuries therefore it may not be appropriate in every circumstance to attempt resuscitation, although a patient may not be in a position to make this decision themselves.

Liverpool Care Pathway The LCP was designed to act as a single, structured record for healthcare professionals when patients were thought to be approaching the last few days or hours of their life. Its aim was to provide guidance to ensure that patients remained comfortable and were only receiving treatment that would be of benefit to them.

A review of the Liverpool Care Pathway was requested in 2012 by Care Minister Norman Lamb following intense media scrutiny into its use. Although upon review of secondary care complaints, specifically related to the use of the pathway were limited, it was felt that the use of the word 'pathway' creates confusion and can be misleading for patients, relatives and carers along with confusion in what the pathway means in relation to treatment. The media scrutiny was particularly related to the perceived withdrawal of food and fluids along with treatment, compounded by a lack of communication between healthcare professionals and families.

The subsequent report, led by Baroness Julia Neuberger was released on the 15th July 2013. The report recommended a phasing out of the LCP within the next 6-12 months. The use of a care plan at the end of life is necessary however it requires effective communication with all parties as to why decisions have been made and why this will benefit the patient. Ensuring that this is in place is a priority over the next 12 months.

5.0 Future Priorities

5.1 Training Priorities – Nursing Homes and Social Care Teams

A 2 year strategy has been put in place to deliver end of life tools training to all care homes in Halton, which will also be monitored via the Care Home contracts, managed by Halton Borough Council. It is anticipated that by 2015 all care homes within Halton will have been part of the Six Steps Training Programme

In addition, key champions who have been identified within Social Care teams will be integrated into the existing key champion's network established across care homes. This will allow the transfer of knowledge across settings and the potential for shadowing across health and social care to ensure that best practice and knowledge is shared.

5.2 Coordination of Care

A priority for 2013/14 is the implementation of an Electronic Palliative Care Coordination System (EPACC's) recommended in Dying Well at Home: The Case for Integrated Working. This system is an electronic information system which will operate across primary, community and secondary care to ensure that all health professionals involved in a patients care are aware of what care plans and decisions have been put in place for that patient.

Halton CCG are currently working with the North West EPACC's project lead to design an implementation plan to ensure that the system is able to operate effectively alongside the current systems. This will include pulling together a steering group within Halton so that we are able to deliver this work by 2015.

5.3 Care in the Last few Days/Hours

As highlighted, a key priority is to ensure that the Liverpool Care Pathway (LCP) is replaced with a care plan that is reflective of individual patients' circumstances in the last few days/hours of their life. This replacement care plan will be coordinated by the Integrated Care Network (ICN) (See Appendix 1) which is represented by stakeholders from primary, community and secondary care and will be implemented via the Advanced Care Planning Team across Halton.

5.4 Bereavement Support

2013 will see the commencement of the build of a new Family Support Centre with "Men's Shed" facility incorporated. In 2012 the Department of Health identified £60 million of funding to support hospices across England to implement projects that would improve the physical environment of hospices (Help the Hospices, 2013). Applications were assessed in collaboration with Help the Hospices and following a bid, Halton Haven Hospice was successful in securing funding. The facility aims to deliver:

- Dedicated, purpose designed space to support families.
- Dignified, unobtrusive access to the service without the potential trauma of people having to access support through the In-patient Unit or Day Hospice.
- An innovative approach to meeting the particular needs of bereaved men through integrating a "Men's Shed" space into the new building.

6.0 POLICY IMPLICATIONS

6.1 This report is in line with national policy guidelines.

7.0 OTHER/FINANCIAL IMPLICATIONS

7.1 As outlined funding for the building of the new family support service was secured via Halton Haven Hospice from the Department of Health Grant Funding. Halton CCG is supporting this work by providing

funding for a coordinator post to ensure the service is delivering its intended outcomes.

8.0 IMPLICATIONS FOR THE COUNCIL'S PRIORITIES

8.1 Children & Young People in Halton

Aspects of the service will meet the needs of children and young people requiring End of Life support and care.

8.2 Employment, Learning & Skills in Halton

None identified.

8.3 A Healthy Halton

The "End of Life' service promotes high quality care for all Adults at the End of Life in different settings including, discussions as the end of life approaches; assessment, care planning and review; co-ordination of care for individual patients; and care after death.

8.4 A Safer Halton

None identified.

8.5 Halton's Urban Renewal

None identified.

9.0 RISK ANALYSIS

9.1 A key risk is the need to ensure that the LCP is replaced within the next 12 months. It is necessary for close working arrangements across agencies continue overseen by the ICN Board to deliver this.

10.0 EQUALITY AND DIVERSITY ISSUES

10.1 The service aims to meet the end of life needs of vulnerable people and will therefore have positive impacts for these groups.

11.0 LIST OF BACKGROUND PAPERS UNDER SECTION 100D OF THE LOCAL GOVERNMENT ACT 1972

Document	Place of Inspection	Contact Officer
End of Life Care Strategy: Promoting High Quality Care for all adults at the End of Life, 2008	Department of Health (DH)	Department of Health (DH)
Dying Well at Home: the Case for Integrated Working, London: SCIE, 2013	Social Care Institute for Excellence (SCIE)	Social Care Institute for Excellence (SCIE)
Committed to carers Supporting carers of people at the end of life, 2012	Marie Curie	Marie Curie
National End of Life Care Programme (NEoLCP), 2010, The Route to Success in end of life care – achieving quality in	National End of Life Care Programme (NEoLCP)	National End of Life Care Programme (NEoLCP)

care homes.		
Six Steps, 2011	End of Life Care Network	End of Life Care Network
End of Life Facilitator Report, October 2010-June 2013	Halton Haven Hospice	Averil Fountain

Appendix 1; *Current Model of Clinical Support at End of Life*