

# Developing an Asset Based Approach Within a Learning Community – Using End of Life Care as an Example



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# Introduction

## Background

In early 2016 Health Education England (HEE) commissioned the National Council for Palliative Care (NCPC) to undertake a project to look at a variety of different and new ways to build a more sustainable asset based approach to workforce development. As end of life care (EoLC) has already adopted this approach more widely much of the learning and key principles are transferrable to other areas including learning communities. This work sits as part of several work streams, which help HEE fulfil its requirements in terms of the Choice Commitment (*Choice in end of life care: government response – Department of Health (DH) July 2016*) and as a member of the **Ambitions for Palliative & End of Life Care Partnership**. For more information visit the website [www.endoflifecareambitions.org.uk](http://www.endoflifecareambitions.org.uk).

Other work streams include:

- Work commissioned by HEE with Skills for Health (SfH) and Skills for Care (SfC) to expand the Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life (2014) into a Core Skills Education and Training Framework for End of Life Care, with Tier 1 incorporating and supporting an asset based approach [www.skillsforhealth.org.uk/eol-cstf](http://www.skillsforhealth.org.uk/eol-cstf). This framework has been developed to align with the current Dementia, Mental Health and Learning Disabilities Frameworks under the banner of the Person-Centred Care Framework, which will be launched in July 2017.
- Strengthening the inclusion of end of life care within undergraduate and postgraduate curricula.
- Supporting Community Education Provider Networks (CEPNs) to include end of life care and an asset based approach in their work.
- Including end of life care in its wider workforce planning as part of Sustainability and Transformation Plans to deliver the NHS Five Year Forward View.
- Working with NHS Employers to influence employers to invest in end of life care training and education through providing end of life care resources. A number of resources and web pages including case studies, top tips and signposting to training and education are available to staff at [www.nhsemployers.org/endoflifecare](http://www.nhsemployers.org/endoflifecare).

- Supporting the roll out of the end of life care e-learning modules via e-ELCA (End of Life Care for All) [www.endoflifecareforall.org.uk](http://www.endoflifecareforall.org.uk). As well as learning pathways for various staff groups, including social care and volunteers, there are 14 e-learning sessions available on the public-facing website.
- Continuing to work closely with voluntary sector partners on specific projects to improve end of life care in hospitals and all other settings where care is delivered.

In recent years, the continuing determination to improve the quality of end of life care has led to refreshed and updated government strategy and policy, as well as numerous publications in the form of research, resources, plans, guidance, standards and recommendations. A full list of these publications can be found on the NCPCC website [www.ncpc.org.uk](http://www.ncpc.org.uk).

## **An asset based approach in end of life care**

A significant amount of end of life care continues to be provided outside of the statutory sector. To provide the best possible seamless approach to care for individuals and their families it requires creative utilisation of statutory, community and voluntary sector capacity and capability to facilitate the sharing, exchange and development of common resources (assets). As a result, end of life care services are ideally placed to adopt and extend an asset based approach. Those providing the services will already be familiar with the approach, even if unfamiliar with the terminology, enabling the learning to be used more widely.

For many years end of life and palliative care networks have existed and valued by those involved, and some of these networks have struggled to continue due to organisational changes within the statutory sector. However, the ongoing resilience by those organisations and individuals who are members has meant that many of the networks continue to come together to share and influence the direction of end of life care, as well as offering support to new and existing members. In addition, many end of life communities have taken the initiative themselves to come together, share systems of support and activities to raise awareness using volunteers as well as help from local hospices or facilitated through the work of networks such as the Dying Matters Coalition [www.dyingmatters.org](http://www.dyingmatters.org).

## About this report

The aim of the report is to be a practical guide to help extend the asset based approach already existing in end of life care into a learning and development model. The national documents that have been used to help formulate this guide are referenced in Annex 1, also included are publications related to asset based approaches more generally.

The report has been divided into two parts to make it accessible to those wanting a quick guide as well as those more interested in the background and research base. **Part one** forms a short summary of the work and provides detail on what an asset based approach can look like and what factors need to be in place, incorporating lessons learnt, case studies and tips from those who have already explored the approach. Plus, examples of innovative resources that can be used to support learning facilitators. **Part two** looks more at the project brief, methodology and the underpinning literature, plus provides additional case studies and further detail on the work of Dying Matters and Dementia Friends, both networks bringing together communities to support end of life care raising awareness activities, which also offer valuable opportunities for workforce learning and development.

## Terminology

One of the main issues encountered has been around terminology. Talking about an asset based approach has caused some confusion amongst those taking part in the review phase, however publications around asset based approaches suggest this is not uncommon. Most asset based approaches identified by those contributing focussed on raising awareness activities around end of life care more generally, rather than activities to increase capacity and support in the workforce, which is the primary scope of this project. In part one this is looked at in more detail and how to adapt the model for learning and development of the workforce.

The description agreed for the review phase was:

*‘An asset based approach should build on resources (assets) within a learning community that can be brought together to deliver end of life care learning to meet common goals, and can vary depending on the skills, knowledge and connections within each community.’*

What makes this approach different from traditional examples of partnership working across sectors is that it should bring together an extended range of participants within a learning community working together to identify existing and new assets that can be exchanged and shared.

It should help to stimulate and motivate change to increase capacity in learning and development activities available and become a normal way of working, but be flexible dependant on need and circumstances so that it does not become too formalised and structured and cease to be effective.

It does not replace the need for investment in education and training but is a methodology to maximise the effectiveness and impact of resources (assets) across a learning community at a time of constrained funding.



# Part One - A Practical Guide

## Introduction

The main aim of using an asset based approach within learning communities should be to build capacity and support to improve care for people nearing the end of their lives and their carers during this time, and those experiencing grief and loss following the death. Specialists providing palliative care services and generalists working in services across sectors where end of life care is included in the service provision, are under pressure as demand for services increases and expectations grow around the range of support available, all at a time of limited funding. To meet demand and expectations generated through national guidance such as the **Ambitions Framework** will require *'educational and service providers to use to their full potential the opportunities for learning and development that exist locally, and where needed to develop new opportunities'*.

Building capacity is not just about creating more of the existing workforce profile. The future end of life care workforce needs to be able to respond to new care models with differing skill sets, skill mix and utilisation of new roles to be able to deliver care across a wider range of settings.

An extract from **'Five ways to improve patient care and staff morale'** – Dr Nav Chana, Clinical Adviser for Workforce Redesign, New Care Models Programme and Chair of the National Association of Primary Care – 2 Feb 2017 NHS England

So, how do we keep people healthier and happier at the same time as nurturing our workforce? Here are five ways to guide the approach:

**1. Change the model of care, rather than fixating on staff numbers** – the 'assets' (i.e. staff) we need to make improvements are already at our disposal and we must work with and involve them continually. The experiences from the vanguards tells us that the dedicated staff you have are the staff you need but they may need help in developing their skills so that they are able to deliver care differently.

**2. Use analysis of population health to drive workforce modelling** – take an approach that is 'blind' to organisational or professional boundaries, where the focus is on groups or communities of people with similar needs and develop your team around that common cause. This way, new roles or extra capacity are not needed.

**3. Be pragmatic** – do what you can rather than wait for the perfect solution or organisational change. Let's embrace the opportunities for healthcare professionals and patients when we come together and work as one team to achieve goals that are important to patients.

**4. Collaborative not positional leadership** – good leaders connect people. Supporting a culture and appetite for integration rather than individual gain is essential.

**5. Community support** – patients, carers and their support networks, for instance charities and other voluntary groups, are a key part of the future workforce – include them in their care and listen to what they say!

## Why champion an asset based approach?

End of life care services have historically come together through cross sector networks to share resources (assets) and should be ideally placed to extend this model into learning communities.

The principles of an asset based approach within a learning community are that it should facilitate bringing together an extended range of participants within the learning community to work together to identify existing, new and innovative assets that can be exchanged and shared to achieve those goals.

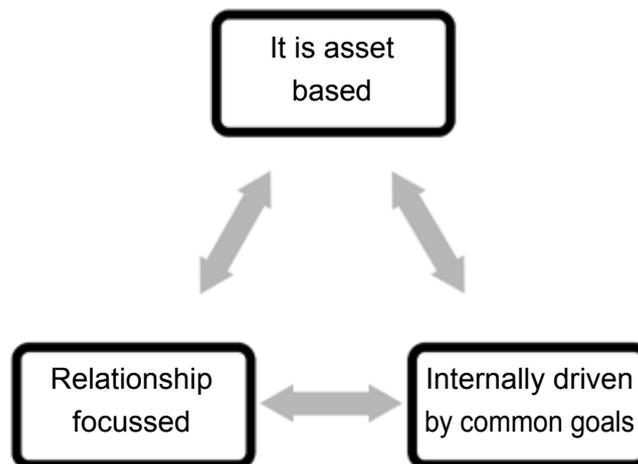
The traditional approach to workforce learning and development focuses on training needs, gaps and problems, and it will usually result in solutions being bought in. Learning communities coming together with a common goal to understand, share and exchange assets will improve capacity, reliance and sustainability, as well as reducing the need to buy in solutions from outside of the community.

Ideally sharing and exchanging of assets should be on an equal basis. For example, if one partner develops an innovative approach to learning and shares the approach it can lead to disappointment and bad feeling if another partner makes a charge to disseminate the approach beyond the learning community without agreement from the other partners.

An asset based approach cannot replace all traditional approaches to investment in education and training, but it can provide an effective alternative solution and can maximise investment previously made by individual organisations and groups by becoming a partner in the learning community.

HEE has a role in supporting those individuals, groups or organisations that are key to connecting local learning communities and developing an asset based approach. Community Education Provider Networks (CEPNs) working with existing End of Life and Palliative Care Networks can be particularly instrumental in this.

This guide will provide detail on what an asset based approach can look like and what factors need to be in place, incorporating lessons learnt and tips from those who have already explored the approach.



## What defines an asset

Within a learning community assets are likely to fall within five main groups:

### Talents and skills of individuals

These are assets individuals bring through their wealth of knowledge, skills, expertise and experience, time and commitment. Everyone has their own story and bringing them together can act as a catalyst for generating other often more resilient assets beyond roles.

#### Examples:

- Trainers and educators – developers of programmes and products.
- Professional medical, clinical and therapeutic staff.
- Professional social care staff.
- Care staff across sectors.
- Expert volunteers, individuals and their families receiving end of life care willing to share their experiences and values (stories, heritage and local identity).
- Project managers and others with business and organisational skills e.g. IT skills and grant writing skills.
- Leaders at all levels.
- Anyone who brings a unique talent, skill or passion to achieve the common goal.

### Groups and networks

Informal/formal groups and associations that reach beyond organisational boundaries.

#### Examples:

- EoLC Facilitators and Champions.
- Dying Matters Coalition – national and local groups.

- Local support groups – Age UK, CAB, lunch clubs.
- National / local charity and voluntary services.
- Local hospice support groups and fundraising groups.
- Volunteer network meetings.
- Service network meetings.
- Mailing lists, databases, newsletter lists, events, connection.

## Organisations

The range of organisational types represented across a community usually employing the staff bringing professional skills and expertise to an asset based approach, as well as usually being the holders of major physical assets and the main investors in education and training provision.

### Examples:

- Health care organisations including local HEE area offices and Hospices.
- Educational and training organisations.
- Social Services and Care Homes.
- Grant giving organisations (those that provide grants to local / national initiatives to support learning across end of life care).

## Physical assets

Land / property / buildings / equipment.

### Examples:

- Meeting rooms, buildings.
- Training / resource centres.
- Equipment (printing), notice boards.

- Internet / intranet, websites.
- Refreshment facilities, tables, chairs.
- Venues, presentation equipment.
- Transport.
- Media outlets.
- Existing community events.

## Connection

A key asset is the ability to build on existing connections and be open to making new connections to enable the exchange and sharing of assets between individuals, organisations and groups and networks. The ability to make and sustain connections is a significant asset that should be valued by the learning community.



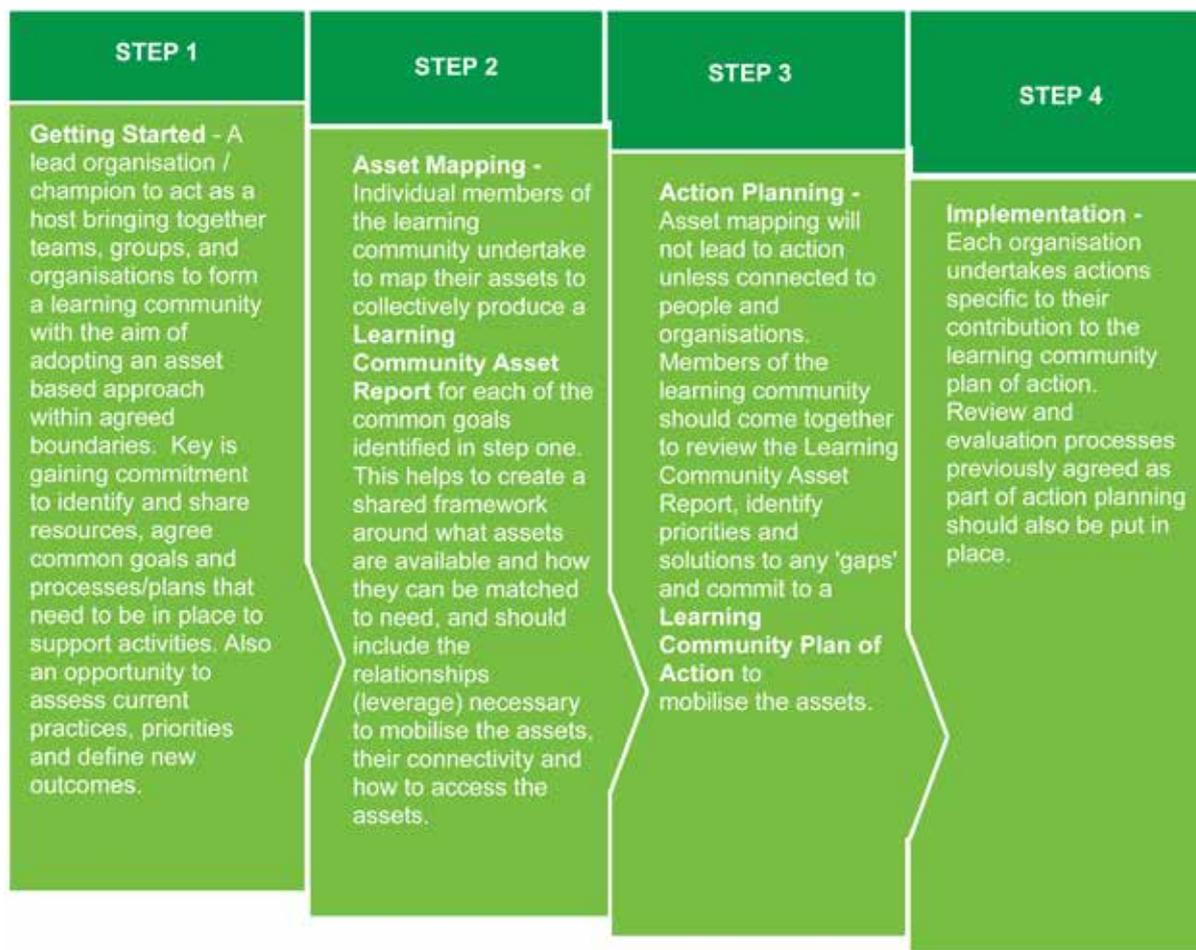
## How to achieve an asset based approach

An asset based approach involves a community coming together mapping their assets and capacity, building relationships, developing a common vision for the future and leveraging internal and external resources to support actions to achieve it. As a process four main steps are involved (fig.1).

Whilst it may help to bring about more effective and efficient use of prior investment by members of the learning community, it should not be seen primarily as a no cost or money saving option. In step 1 discussions around funding and subcontracting may be included if financial resources are available

*To achieve true asset sharing and exchange, agree common goals and connectivity takes time.*

Fig .1



In **Step 1** a host organisation / group will bring together potential partners to form the ideal learning community within a defined boundary to agree common goals and seek agreement to adopt an asset based approach. Members of the learning community should identify the individuals to undertake and coordinate the asset mapping as part of Step 1.

Whilst not focussed primarily on an asset based approach to learning as described for this project, case study 1 provides a good example of a model of partnership working where organisations came together with a common aim, and could develop a wider asset based approach to learning given the connectivity and good will already established.

### Case Study 1 - Dorset End of Life Care Education Group

**Context** – The work dates to 2000. The workforce group in Dorset originated as part of the national money allocated within the Cancer Plan and through the End of Life Care Strategy. The group originally was a subgroup of the Dorset Cancer Network. Dorset also was an early site for the Gold Standards Framework (GSF) with two appointed facilitators – Dorset became a regional centre, which was transferred from the Clinical Commissioning Group (CCG) to Weldmar Hospicecare in 2014. The group has always been provider led with a strategic lead chair that plugs into the National Picture either via the Cancer Network, Strategic Health Authority (SHA) or Primary Care Trust (PCT) and then CCG. Membership is from across East and West Dorset. There is NHS, third sector, nursing home, local colleges and county council representation. It is currently chaired by the CCG and the group strongly believe that this is key to the success and longevity of the workforce group. They discuss need in relation to national directives and guidance and relate this to the education and training needed by all staff in health and social care in their patch. It has grown over the last 16 years – it is not an instant fix and it has taken time to work well together, trust each other and to see the value added of this approach – even when the original monies are long gone. Drawing on national guidance sub groups are set up to design the programmes. We may charge for attendance but all preparation time is free from all involved.

Programmes are designed and run as a pilot and evaluated ahead of rolling out across the patch at three of four key sites – drawing on local up to date practitioners to co-teach across the sites. It is also a “swap shop” for information and a place for sharing programmes that are being run out with the group to share. It is a true collaboration but started with a pot of money to bring people to the table. It is a place for discussion and innovation.

**Additional benefits** – Standards of care are maintained through the education provided and sharing of current good practice. The model has been replicated across the Tissue Viability and Pressure Ulcer group in the CCG – ensuring that good practice and education is shared and breaks free from the silo approach.

**Caution** – It only works on the commitment and good will of those who attend. There is increasing clinical pressure and the balance of clinical / teaching time is now a tension. It also only works with “seed funding” – as group we make this grow – “we make a little into a lot”.

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**Step 2** is about getting the learning community to identify what assets they can contribute and to produce a Learning Community Asset Report. A sample template can be found at the end of part one of the guide and has defined the assets as ‘Individuals’, ‘Organisations’ and ‘Groups & Networks’ to encompass the five main asset groups mentioned previously.

**The following are guidelines for gathering information:**

- A common goal must have been agreed and understood.
- It must be more than just gathering data and information on known assets. It should facilitate discovering new and previously unknown assets, as well as identifying potential assets.
- It should identify existing interconnectivity and facilitate the formation of additional connections and relationships resulting in the potential to expand the learning community and draw in more assets.
- The asset mapping can be undertaken individually but will benefit from a skilled facilitator to bring it together into a Learning Community Asset Report.
- For ‘Individuals’ or ‘Groups & Networks’ face to face conversations or attendance at local meetings/workshops may be required – attendance by a skilled facilitator would be beneficial.

- Be clear about the availability and accessibility of the asset – for example is it available for the duration of the activity required to achieve the common goal, will there be some cost for use of the asset, are there issues around access to the asset, such as costs for training rooms / venues, days staff may be unavailable to contribute, restrictions in travel.

The following case study (2) also shows excellent connectivity with a broad range of partners and an approach to asset mapping.

### Case Study 2 – Cheshire Living Well, Dying Well

Cheshire Living Well, Dying Well (CLWDW) is a public facing brand for The End of Life Partnership, a charitable collaborative in Cheshire aiming to transform End of Life Experience and Care. Stakeholders include four Cheshire Clinical Commissioning Groups (CCGs), two local authorities (Cheshire East and Cheshire West), three hospices, three hospital trusts, the University of Chester, Carers Trust for All and Macmillan Cancer Support. The dedicated CLWDW Community Partnership also enables community voices to be heard with membership from a variety of health and social care organisations, housing organisations, local businesses, Cheshire Police, Cheshire Fire and Rescue Service, church and faith groups and various community and voluntary organisations and groups.

Further information can be found at [www.cheshirelivingwelldyingwell.org.uk](http://www.cheshirelivingwelldyingwell.org.uk)

The Public Health and Wellbeing Team within the organisation, alongside CLWDW Partnership representatives and community champions are leading and involved in a range of projects to enable people to live, age, grieve and die well. This includes the following:

- Delivery of wide-ranging Public and Community Public Health & Wellbeing Projects and Skills Workshops to increase community capacity, resilience and future life planning.
- Delivery of training to enable people who work with the public to engage and empower service users and the wider community to think about, talk about and take action in relation to life, age, death and loss.
- Targeted support training for health and social care staff.

- Bespoke resource development.
- Community-led and developed workshops/awareness-raising initiatives.
- Consultation and focus groups.
- Knowledge Exchange.
- Development of 'CLWDW Compassionate Community Volunteer Models'.
- Adding to the understanding as to what influences knowledge, attitude and behaviour change and impact upon wellbeing re: ageing and end of life issues.

**The End of Life Partnership** also hold sessions to support building resilience and compassion in the workplace. They are for attendees to be confident and competent to enable, inspire and empower a compassionate team approach (personal/professional) in the workplace. The sessions involve the facilitation of asset mapping processes and the opportunities to fill any gaps. Attendees are supported to then plan and identify the required next steps to implement any changes, as appropriate.

**Rachel Zammit, Head of Public Health, Quality and Communication, The End of Life Partnership** - [Rachel.Zammit@eolp.org.uk](mailto:Rachel.Zammit@eolp.org.uk)

Several contributors referred to 'skills sharing' exchanges, often between staff in two or three organisations and usually on a semi informal basis. Many of these local exchanges are very successful but may not be widely recognised as an asset based approach model. They can be useful when building a case for introducing the concept of a community wide asset based approach especially when seeking high-level engagement from members of the community. Case study 3 from Dorset shows a good example of local skills sharing. It demonstrates that whilst the original learning activity had received funding, when it ended there was an agreement to an exchange of assets which supported the on going sustainability of the original investment without further direct costs.

Once a **Learning Community Asset Report** has been produced the members should come together (**Step 3**), including any new members identified as part of the process, to review and identify any gaps before producing the **Learning Community Plan of Action** (see end of part one for a sample template). This will include agreeing plans to resolve resource gaps, such as buying in expertise not within

the learning community or expanding the number of potential members to access additional assets. It is also important to ensure monitoring and evaluation processes for an activity are agreed and in place as part of Step 3.

### **Case study 3 - Weldmar Hospicecare Trust and Dorset County Hospital Foundation Trust (DCHFT)**

Originally in 2013 Weldmar Hospicecare Trust developed a programme training End of Life Care Champions for the hospital. Each ward identified one trained nurse and one healthcare assistant to attend. They attended study days in the hospice and a 'learning in practice' day, including placements at local funeral directors as well as health organisations. The programme was funded by the Burdett Trust for nurses following an application for a grant for the programme. This programme was written up and a poster was taken to the Palliative Care Congress in Harrogate the following year. Once the funding had been used, there was felt to be a need to embed the Champions more to make it sustainable. Action Learning Sets were an opportunity for doing this.

Weldmar offered to organise and facilitate the action learning sets in exchange for clinical skills training for some of their staff. This worked extremely well. Three action learning sets were delivered in DCH by Weldmar and six of the hospice staff received blood transfusion assessors training or cannulation training in exchange - **Caroline Sweetland, Lead Education Facilitator, Hospice Education Alliance, Weldmar Hospicecare Trust -** [caroline.sweetland@weld-hospice.org.uk](mailto:caroline.sweetland@weld-hospice.org.uk)

**Step 4** is about mobilising assets to deliver the activities, incorporating the monitoring and evaluation process agreed as part of Step 3.

The following case study (4) has been extracted from 2014 BMJ article *End-of life conversations and care: an asset based model for community engagement* and demonstrates the four steps.

### **Case study 4 - Cumbria Conversations for Life**

This case study outlines the development of an innovative public health initiative initiated in response to local health, social care and voluntary agency interest. Cumbria Conversations for Life was a county-wide pilot initiative co-branded and funded by NHS Cumbria (lead organisation) under a Healthy Communities public health initiative.

The project had the following aim:

- To improve awareness about, and increase, advance care conversations among the general population using a public health campaign.

The objectives were to:

- Break the taboo of talking about death and dying while healthy.
- Help the public consider options and improve access to local resources.
- Support people to learn how to begin conversations to influence their care for the future.

'Advance care conversations' refers to a public health approach to conversations between family members preparing for future care needs rather than the completion of specific advance care planning paperwork associated with health bodies. Given interest from multiple local leaders, and under the auspices of the lead organisation (**step 1**), the project was led by an independent project lead and overseen by a multiagency project steering group (local leads) that informed and guided the work. Membership of the steering group represented local hospice and specialist palliative care organisations, primary care, public health, social care. At a launch meeting of the project steering group, a facilitated mapping of assets, local resources and networks began (**step 2**). Over the course of eight meetings, the public awareness campaign was planned (**step 3**) and implemented (step 4).

This campaign comprised three elements:

**1. Stories:** A DVD (*Breaking the Silence*) was produced and presented eight local people's stories of experiences of conversations and care, both with their loved ones, and their own reasons for wanting to talk about and plan for their future.

**2. Outreach and information:** Branded promotional and resource materials (web and print) were developed for outreach activities. A website provided signposting to national and local information and resources. Posters and flyers were distributed through partner health and social care organisations and agencies. Local media such as radio and newspapers were used to raise the profile of the campaign.

**3. Education:** Eleven facilitated training workshops about end of life conversations and care were held across Cumbria in six locations. The DVD was presented and conversation cards used to facilitate individual awareness, practice talking about these issues and identify personal actions to take arising from the workshop. The participants included members of the public and professional staff. An evaluation of each workshop was undertaken using a short survey form and analysed using descriptive statistics and a coding of responses to open questions.

Note: With thanks to **Mary Matthiesen** at **‘Conversations for Life’** for allowing the reproduction of this case study - [www.conversationsforlife.co.uk](http://www.conversationsforlife.co.uk).

The case study (5) from St. Giles Hospice is not directly related to learning but demonstrates many key aspects of an asset based approach to increase service capacity as well as recognising volunteers as valuable assets. It won the 2016 NCPC Bereavement Project of the Year Award.

### **Case Study 5 – Bereavement Help Points (BHPs)**

St Giles Hospice covers both a rural and urban catchment area, including nine major towns. The project has been to work in partnership with other service providers to develop a Bereavement Help Point (BHP), which operates in each of these towns. The vision is to give bereaved people a place where they are able to access information and support, where they can talk to others and share their emotions with the flexibility of it being locally based and accessible when they feel they need support.

The BHP service is volunteer led with regular supervisory support provided by St Giles for all those involved. Given the scale of the project, it was clear that partnership working with likeminded organisations would be imperative. The approach to setting up the BHP began with St Giles scoping each locality, identifying relevant local partners and sourcing a suitable venue. Partnerships were explored according to shared values and philosophy and agreements were drawn up between all partners for each of the BHP. St Giles work in partnership with a variety of organisations including Cruse Bereavement Care South Staffordshire, Cruse Derby and Burton, Queen’s Hospital Burton (NHS), The Dove Service, Age UK Burton, Staffordshire Fire Service and Sacred Heart Church, Tamworth. **(Step 1)**

Bereavement Support Volunteers from partner organisations were then recruited, and engaged into the project. Their 'buy in' to the vision and joint nature of the project was essential to its success, consulting with them throughout the development phase was key. The success of the BHP's also relied upon sourcing a room that is comfortable and welcoming, available in the right location. Although organisations offer rooms free of charge, their location does not always lend itself to accessibility for bereaved people, recently as a result of feedback and a review the decision was made to relocate one of the help points into a more central and accessible location. **(Step 2)**

**(Steps 3 and 4)** St Giles developed promotional materials for each of the seven help point. Flyers were distributed to local health centres, hospitals, pharmacies, church groups, funeral directors and any organisations who may deal with bereaved people. Press releases were also provided for local media. The partners who have been involved in the projects have also promoted the BHP's through their existing communication channels, including via the advice and referral centre at St Giles, Bereavement Help Line at Cruse and word of mouth with other organisations.

Prior to the launch partner organisations and volunteers met and agreed how the service operates, including:

- How the weekly rota will be organised.
- How complaints and concerns will be dealt with.
- How supervision will be available.
- How the service will be evaluated.
- How volunteers can contribute their views and ideas to the on going development and progression of the BHP.

A review of each BHP has been held three months post launch with on going review meetings being held with partners on a 6-monthly basis. The on going operational management of the BHP's is undertaken by the volunteers with back up support from the project manager as required to address any issues.

From an organisational perspective, the BHP's have enabled St Giles to manage their waiting list for 1:1 support more effectively, maximising the use of limited resources. They also created a cost evaluation, which looked at actual costs set against potential costs. The work showed that to support a bereaved

person costs around a £1 per week. It also showed that if room hire wasn't free and all volunteers claimed their travel expenses, then that cost per week would rise to around £3.40. A fantastic example of the difference that volunteers make and how support can be met at a relatively small cost.

The project brings together the experience of established bereavement organisations, working in partnership to produce timely support for bereaved people. The project is volunteer led with minimum costs to those organisations involved. Across the catchment area, one to one support for bereaved people usually commands a 5-6 week waiting time. With Bereavement Help Points, people are never more than 48 hours away from having someone to talk to and as is often the case, once a bereaved person has accessed one of the bereavement help points, they find they no longer have any need for one to one support. This new and innovative way of supporting bereaved people is the backbone in the compassionate communities' programme.

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## Factors for moving forward

The following factors contributing to moving forward with an asset based approach have been identified from the thematic review of information gathered from contributors, including what they have learnt and the tips offered, as well as from the limited evidence base available. This includes two recent reports which look at community development in relation to end of life care *Each Community is Prepared to Help: Community Development in End of Life Care – Guidance on Ambition Six (2016)* and *Dying Well Community Charter Pathfinder Project – Evaluation Report (2016)* and more detail on these reports can be found in Part Two, neither are specifically related to learning communities but they provide useful insight and background for developing a learning community.

### Board level engagement

Board level engagement has been highlighted as the main driver to make things happen, as well as the major barrier to progress. The following are general guidelines for engaging with organisational Boards, and to fully implement an asset based approach there are likely to be several Boards across a range of partner organisations that will need to be engaged.

<p><b>Preparation is key!</b></p> <ul style="list-style-type: none"> <li>• The individual or group who want to introduce an asset based approach across a learning community must be well prepared as the business case being presented must stand out from others vying for attention.</li> <li>• If your idea is not well thought through and presented the Board will not take you or the idea seriously.</li> <li>• See the section on 'Why champion an asset based approach' to get started.</li> </ul>	<p><b>Prior Engagement with a Board member(s)</b></p> <ul style="list-style-type: none"> <li>• Ensure there are no surprises on the day of the presentation.</li> <li>• Allow the Board to have longer to digest the idea and benefits.</li> <li>• Help tailor your message.</li> <li>• Gain an advocate(s) on the Board.</li> <li>• Help to give the Board a sense of ownership.</li> </ul>	<p><b>Clearly and concisely define and understand what it is you are suggesting</b></p> <ul style="list-style-type: none"> <li>• Clearly describe your idea and what is needed - if you aren't clear how can you convince others!</li> <li>• Show why it is important.</li> <li>• How it will benefit the organisation - remember an asset based approach isn't all about finance!</li> <li>• Prove that it fits with the organisation's strategic plan and national/local policy.</li> <li>• Highlight the potential consequences of not moving forward.</li> </ul>
<p><b>Understand the drivers of the people on the Board</b></p> <ul style="list-style-type: none"> <li>• With the Chief Executive/ Chair who are involved in all aspects of the organisation they will only have time for headline issues - aim to focus on how it meets the strategic plan and negative consequences of not doing it.</li> <li>• Finance/Business Directors will generally see a numbers game - if possible identify the impact on increased productivity and capacity building.</li> <li>• Clinical Directors of services will want to see the impact on increased capacity to deliver their services.</li> <li>• Planners and commissioners will be interested in potential increased capacity and benefits of shared services.</li> <li>• HR/Workforce Dev. Leads will want to maximize L&amp;D investment.</li> </ul>	<p><b>Into the Dragon's Den</b></p> <ul style="list-style-type: none"> <li>• Your preparation should mean you have a good understanding of your ideas, the benefits and the reasons why an asset based approach should be implemented.</li> <li>• Be yourself - it will make the presentation and message more believable.</li> <li>• Listen carefully to responses, comments and questions and record any questions as you go.</li> <li>• You should already have board members on side so refer to previous conversations and agreements from your preparation to transfer some ownership.</li> <li>• Make sure you are clear on the decision they have made and any commitment agreed, as well as the next steps and timeline for reporting back to them.</li> <li>• Agree who your main contact will be.</li> <li>• Don't forget to thank them for their time.</li> </ul>	<p><b>Maintain momentum</b></p> <ul style="list-style-type: none"> <li>• Write up notes from the meeting and recap all key points - seek clarification if needed.</li> <li>• Make sure you keep on top of any actions agreed.</li> <li>• Give regular feedback and progress reports - preferably at the Board meeting to keep it on the agenda.</li> <li>• Ensure all successes, however small, are highlighted to ensure they know that by backing you they made a good decision.</li> <li>• Keep up the network of important connections you have made, especially anyone who has been an advocate or supporter on the Board.</li> </ul>

### **Undertaking the role of Host / Lead Organisation or Group should include:**

- Ensuring Board level engagement and commitment – a member of the Board may need to take a major role in linking with the boards/senior members of other potential partner organisations/groups, therefore they must be well prepared so that they can articulate to each potential partner the nature of the initiative and what is in it for them. It will give reassurance to other potential partners in the learning community if senior people within the host organisation/group are engaged.
- Having access to the following skills to move forward including brokering, facilitation, networking and community development, and having a lead educator/trainer engaged from the start is beneficial.
- Ensuring a team approach is adopted with partners to reduce dependency on a lead individual within one organisation.

### **Securing potential partners buy in**

- It is equally important for all partners that Board level, or those leading groups/networks, engage otherwise it may get blocked if priorities change.
- Senior people from partner organisations/groups coming together initially to commit to the approach must be well prepared/briefed so they can anticipate the discussion and understand what is in it for them, their organisation and their learning community and the incentives that can be utilised to gain wider commitment.
- Those taking it forward should adopt a 'developmental' leadership model. This generally means having the ability to see the potential in others and create conditions for the involvement of all. Therefore, working to 'win hearts and minds' to change to an asset based approach, influence peers, and help others make relationships and work collaboratively. End of life care has benefitted from examples of this leadership style as evidenced by the numerous examples to be found on the NCPC and Dying Matters websites (also see case study 6).
- Have a reality check - some investment may be required to stimulate activity – it is not a no-cost activity.

## Case Study 6 – An Example of a Developmental Leadership Approach

Maggie Tween was nominated for the NCPA End of Life Champion of the Year in 2016 and works as Head of Cancer, Palliative and EoLC - NHS Great Yarmouth and Waveney Clinical Commissioning Group  
[www.greatyarmouthandwaveneyccg.nhs.uk](http://www.greatyarmouthandwaveneyccg.nhs.uk).

Her colleagues who nominated her said:

*“Maggie has been a tireless and driving force behind a long list of palliative and end of life initiatives and service improvements in Norfolk and Suffolk over many years. A central co-ordinating structure of Maggie’s work is the Norfolk and Suffolk Palliative Care Academy, which she planned and successfully set up in 2012. The Academy is a collaborative group of individuals and organisations, which aims to achieve the vision of improved comfort, compassion and dignity for people with a life limiting illness. The stated aim is to give patients more choice at the end of their lives, raise public awareness of issues around death and dying, provide more support for carers and reduce acute hospital admissions in the last year of life. The Academy’s work aims to increase the workforce’s transferable skills so that they can deliver care in all areas more effectively.*

*She has worked tirelessly to pursue these goals. Her passion, energy and commitment to making end of life issues everybody’s business and improve palliative services goes much further than that. She inspires everybody who comes across her to think and talk about palliative care and end of life planning, whether colleagues across health and social care services in Norfolk and Suffolk, women in her local WI group or someone who has turned up at the many public awareness events she has organised.*

*Maggie’s ability to connect with people in public forums and talk in such a way to break down those barriers is truly amazing and at the same time she is able to engage with those at the highest level of service delivery including CEO of acute services, social care and care agencies. She consistently recognises the role everyone plays and embodies this by eloquently and purposefully crossing barriers and challenging any prejudice.*

*She is open, approachable, resourceful and fearless in relation to challenging fixed beliefs and competing agendas, always clearly seeing the link between good end of life care, high care standards and personalised care in general. Resistance and hesitation around end of life and palliative care issues can be challenging but Maggie’s passion, resilience and creative approach can*

*overcome most obstacles. She has an ability to use all mediums to promote palliative and end of life issues – be it in written, spoken, Internet and social media form. This seemingly effortless ability is so effective that it repeatedly brings all stakeholders together with a common purpose around palliative issues and service improvement. Her clarity of thought in translating strategy and ideas into meaningful outcomes is remarkable and rare.”*

Another example of her work has been to initiate and lead work with stakeholders from across the county as well as Maggie’s own local community to set up ‘compassionate communities’ networks. [maggie.tween@nhs.net](mailto:maggie.tween@nhs.net)

### **Understanding the importance of raising awareness and engagement**

- Be aware that knowledge and understanding of an asset based approach is limited and time will need to be spent reaching agreement on this before common goals can be determined and true partnership working is established.
- Be prepared for difficulties engaging people/organisations as the approach often challenges what has previously been taken for granted e.g. an environment of provider competition, and tension between an asset based approach and professional identity/ways of working.
- Look beyond traditional partners for workforce development – seek out others who may have assets that they can contribute e.g. volunteer networks, funeral directors. Use partner networks to raise awareness within the wider community, which may open up new partners (see case study 7).
- Understand and identify any incentives that can be utilised, and make sure each potential partner can identify how they can benefit from the approach. Show potential Return on Investment (ROI) e.g. developing and sharing specialist skills and knowledge can deliver greater increases in capacity than smaller service providers trying to do it on their own. (Also, see increased effectiveness in bereavement services in case study 5).
- Sometimes by calling the initiative a ‘pilot’ it can make some organisations / groups feel ‘safe’.

## Case Study 7 – Examples linked with ‘Conversations for Life’ (CfL)

The approach is an asset based approach so that the existing skills and strengths between systems, staff and in communities can ensure a ripple effect of awareness, education or change. Following work convening multi-sector partners and stories of the public to develop materials for the initial Conversations for Life public and staff awareness initiative resulted in:

a) Feedback from a facilitated, daylong asset based event in the North West with health, county council and third sector voluntary organisation resulted in a number of activities. This included funeral home and care home staff who had attended the event recognising the gaps between services and challenges for each following a resident’s death, and saw it offered a skills share opportunity to educate and raise awareness of both teams so staff and families could achieve a smoother process when a resident died. Also, working with the local hospice to engage the assets of the wider community in raising awareness on end of life conversations and care resulted in an assets/ strengths related report being produced and a multi organisation funding bid for staff to move the initiative forward.

b) Recognising the need and benefit to the wider community:

- Reach and awareness was raised via newsletters by multiple agencies.
- Promotion of awareness/educational events were free of charge for public workshops held in spaces offered for free by county council, Age UK, and community agencies offered spaces for CfL facilitated public workshops as part of a countywide awareness initiative.
- Health and Social Care staff, GP’s and Care Home staff have attended workshops and cascaded the approach and materials in their services, making recommendations to changes as a result (i.e. initiating awareness about ACP awareness via Care Homes to their residents/ families, starting realistic conversations earlier with renal and dementia patients- (Salford and East London pilot projects)

c) Utilising the combined strengths / assets of the Dying Matters Coalition meetings, Greater Manchester Strategic Clinical Network’s investment in film resource development and facilitation process resulted in:

- 150 multi-organisation leaders to input into policies and practices for minority issues in end of life care for the region.
- Existing staff educators across health and social care to utilize the resource to further deliver awareness / education in their service or community.
- Community organizations have the film resource to use for education / awareness.

Mary Matthiesen, Conversations for Life - [www.conversationsforlife.co.uk](http://www.conversationsforlife.co.uk)

### How to ensure sustainability

- To be sustainable it needs to be embedded into the local health and care system strategy as part of the Sustainability and Transformation Plans (STPs), and organisational strategies so that it is not dependent on the enthusiasm of a single person or small group.
- Investment in staff to become good educators/facilitators as part of their role is necessary – see later in Part One examples of resources that can support new facilitators.
- Methodology must be developed to evaluate the approach to generate evidence of efficiency and effectiveness that are robust enough to demonstrate that the approach offers value for money/ROI – important to keep Boards on side. Where appropriate it should also include evaluation on improved skills, knowledge and changing behaviours.
- Keep it simple and flexible – one size does not fit all. The approach will need to be reviewed by all partners in the learning community to ensure it continues to meet the needs of the community so that it can evolve as the community develops.
- Try to ensure all partners feel they are benefitting equally where possible e.g. avoid a situation where one organisation gives assets freely while others who are using them are not as prepared to give in return or put themselves out.
- Identify potential sources to bid for funding for development within the learning community – new partners in the learning community may unlock other opportunities.

*It is not a quick fix and developing asset based approaches within a learning community should be a long-term project to change culture and attitudes. The approach should become the normal way of working and will need to be included in the induction process for new staff appointed to key roles – it can be time consuming.*

## Is an asset based approach replicable and scalable?

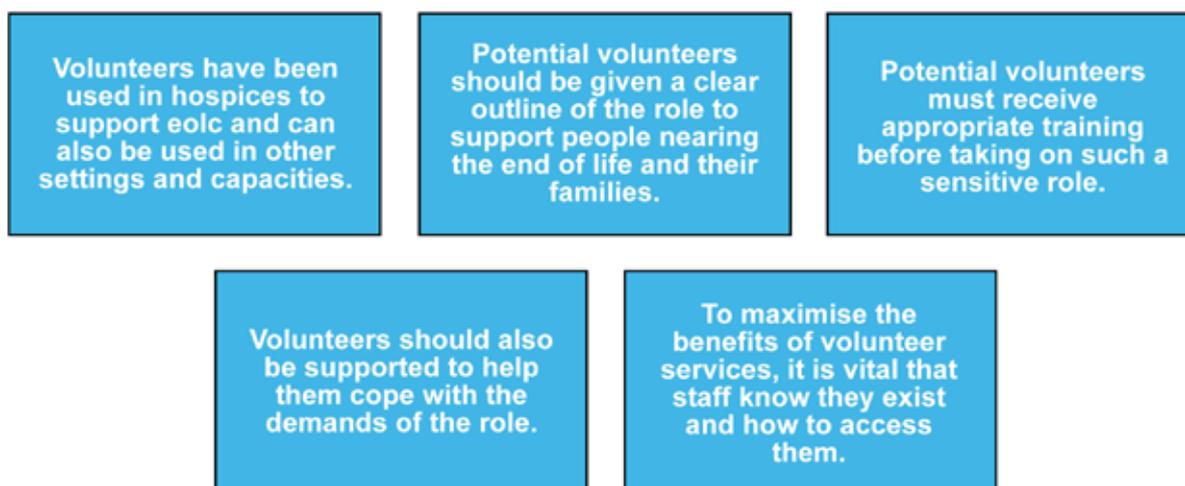
The values and principles of an asset based approach are replicable. As with most successful initiatives strong leadership, commitment and continued evaluation to provide an evidence base to show economic benefits and capacity building are key to embedding this way of working into local strategies.

Local asset based approaches may not be scalable as they rely on specific local needs and differing configurations to be successful, so 'One size does not fit all'.

## Using volunteers as valuable assets to support end of life care

The following are examples of where initiatives to utilise volunteers to increase capacity, fill gaps in end of life care or contribute to professional training have been undertaken. They recognise volunteers as valuable assets and although some funding may be required initially to ensure the volunteers are well prepared and supported, it can often mean other health and care staff can be used more effectively increasing capacity in other areas.

### Five key points to using volunteers as assets



Source: 2016 Nursing Times article referenced in case study 8

## Case Study 8 - Aintree University Hospital Foundation Trust End of Life Care Volunteer Companionship Service

A full write up of this initiative can be found in a 2016 Nursing Times article [‘Using volunteers to support care’](#). The patient/carer representative proposed a volunteer companionship service in end of life care to the Cheshire and Merseyside Strategic Clinical Networks Education Sub Group and the trust’s end of life/supportive care steering group. This was met with enthusiasm and, as a result, a training programme was developed for the volunteers in line with support from both groups. In September 2011, a business case to fund the training programme was presented to Cheshire and Merseyside Strategic Clinical Networks Palliative and End of Life Steering Group and was successful.

**Setting up the service** - A monthly multiprofessional management group comprising a palliative care consultant, palliative care nurse specialist, patient/carer representative and volunteer manager was set up to review the compilation of the training programme and service. The volunteer manager approached 15 individuals from an existing cohort of volunteers who, as a result of their previous experience in critical care or accident and emergency environments, were considered able to cope with the sensitivities of a role in end of life care. A detailed role description was drawn up highlighting the care volunteers should give to patients and their families.

**Training programme** - A two and a half-day interactive programme was drawn up. The programme was developed with guidance from Cheshire and Merseyside Strategic Clinical Networks Education Sub Group in line with the key priorities in the DH’s (2008) end of life care strategy. The training was crucial to the volunteer service’s success; it included theoretical and practical sessions and was facilitated by a multidisciplinary team. In 2012 a three-month pilot was launched on five wards. By February 2016, volunteer companions had responded to 378 requests for patient support. Awareness of the services is continuing to spread nationwide with more requests for information about the training programme. **Conclusion** - The introduction of this service has revealed that volunteers can make a substantial contribution to meet the needs of people who are dying and their families. However, training alone for end of life care is not sufficient; volunteers need to know there is close support with regular supervision as well as psychological and peer support.

**Challenges** - Identifying the right calibre of volunteer and conflict with ward staff that didn’t understand the role.

**Kathy Collins, Clinical Network Manager, Cancer, Palliative & End of Life Care, North West Coast Strategic Clinical Networks and Sharon Bird, Patient / Carer representative, end of life / supportive care steering group, Aintree University Hospitals Foundation Trust and Cheshire and Merseyside Coast Strategic Clinical Network - [k.collins5@nhs.net](mailto:k.collins5@nhs.net)**

Gentle Dusk (case study 9) also provide a volunteer led programme empowering communities to plan for end of life care.

### **Case Study 9 - Gentle Dusk - Future Matters**

Future Matters is a community-based solution to raising awareness of end of life care planning. Volunteers are trained to cascade end of life care planning information to local communities. They can then support members of the public to put their plans in place and help them share their plans with those who will care for them. Volunteers are given the knowledge, skills and tools to become Future Matters Volunteers, or peer educators in end of life care planning. Future Matters Volunteers deliver one to one appointments to help clients plan and write out their end of life care plans including their advance care plan. Volunteers also run workshops for community organisations, which often include care staff in the audience. They can make presentations to a variety of groups (e.g. older persons' forums) and run information stalls at other appropriate events and during Dying Matters week.

#### **Outcomes**

Future Matters is successful and cost effective. In an average size Clinical Commissioning Group (population size 250,000), the following outcomes can be expected:

**Year 1:** 22 volunteers trained, 17 awareness raising events delivered, 260 members of the public reached, 47 end of life care plans completed (including 12 advance care plans).

**Year 2:** 570 members of the public reached through awareness raising events, 105 one to one appointments, 65 end of life care plans put in place (including 31 advance care plans).

Future Matters has been developed, delivered, monitored and improved over a period of 5 years. Gentle Dusk can deliver the Future Matters training

programme and support its implementation in any locality in the UK or deliver the training as a stand-alone training package. A license for the programme and train the trainer option can also be commissioned.

### **Feedback**

**Kayleigh Dolan, Scheme Manager, Anchor** – *'The ladies who came to visit us at Queen Elizabeth Court were fantastic, it was such an informative yet fun session. At the end, all those who attended were in quite high spirits with lots to think about. Since the session many who attended have now decided to get in contact and set up their own Advanced Care Plan with the help of Future Matters. Thanks for all your help.'* [www.gentledusk.org.uk](http://www.gentledusk.org.uk)

The case study (10) from St Christopher's Hospice demonstrates the utilisation of patient led groups contributing to student clinical education.

### **Case Study 10 – St Christopher's Hospice - The Goldfish Bowl**

Student clinical education is an important part of the educational stream at St Christopher's. They have a long-standing relationship with a local teaching hospital to offer a half-day 'introduction' to palliative care to 5th year medical students. One part of this education is the Goldfish Bowl.

The Goldfish Bowl is a patient led group who 'teach by experience'. The group lasts for 50 to 60 minutes and in the main, it is the patients who speak, describing their experience of diagnosis, hospital appointments, treatments and what is felt like to be referred to a palliative care service. Within these open questions, attendees talk not only about their physical symptoms and the effect of treatment, but also describe how healthcare professionals spoke to them, what waiting for transport or being admitted to a busy ward feels like and, how the opportunities to engage with a hospice, where the emphasis on quality of living prevails differs from secondary care.

Until the last 10 minutes or so of each goldfish bowl, the medical students are not permitted to ask questions or make any comment. They are, in effect, passive observers to a facilitated conversation. The facilitator is a member of staff at the hospice with a clear intention only to ensure that all those who are willing to participate have opportunity to speak.

Recruiting participants can be complex. Goldfish bowls for medical students occur monthly during the academic year, but their success and impact means other groups visiting ask for a goldfish bowl as part of the learning experience. This presents a serious issue - recruiting sufficient new participants so those who have taken part previously do not feel burdened by being asked too often.

The following will illustrate the impact of this means of patient led learning. Michael was a 67 year old man. He was a retired hospital consultant who had been diagnosed with a progressive neurological condition. His speech was not easy to understand, so his participating meant a great deal of energy was devoted to the experience. Students had to actively listen to him to benefit from his contributions. He spoke initially of his decision after diagnosis to travel to Switzerland and had made plans to do so. He was able to speak of a reduced quality of life and his fear of the uncertainty around his progressive illness, which had led to this decision. As the goldfish bowl moved through the series of questions, Michael talked of referral to the hospice and the opportunities to use the gym, engage in art based activities, be seen by a clinical nurse specialist while he was at the hospice and make friends with other patients, the staff and volunteers. This he reflected had led to his choosing to postpone the journey to Switzerland as he now felt that his life had a quality which meant he no longer felt there was no reason to remain alive. The students, during their opportunity to ask questions, honed in on the clarity of his change of mind and engaged with his understanding of quality of living.

The Goldfish Bowl is consistently highly evaluated by students after their half-day visit, and among the experience of the half day is the single element in which the medical students hear first-hand the 'voice of the expert'.

The concluding question for patient participants is always 'have you got a message for the students?' Invariably the responses centre on listening, compassion and responding; treating each person as an individual taking the time to ensure that the patient is given opportunity to ask the questions they need to ask, and be answered with honesty.

**Heather Richardson**, [H.Richardson@StChristophers.org.uk](mailto:H.Richardson@StChristophers.org.uk) and **Rev Andrew Goodhead** [a.goodhead@stchristophers.org.uk](mailto:a.goodhead@stchristophers.org.uk) – **St Christopher's Hospice**

## Useful innovative resources to facilitate learning

The following examples highlight some of the innovative resources that have been developed to support learning and development in end of life care, and could be included as useful resources to support facilitators within a learning community planning staff development activities.

Finity have developed a manual (resource 1) to guide facilitators when delivering a range of end of life issues in a workshop. The value of this resource to a learning community is that it can be used as a practical tool to help develop new facilitators to be confident to organise and deliver learning as part of an asset based approach.

### Resource 1: Finity – Preparing for Death, A Workshop Manual for Facilitators

In 2013, Wendover GP Dr Jo Withers, together with a like-minded colleague, founded Finity to give her local community the opportunity to consider and explore end of life issues. Finity's aim was to offer an environment where it was acceptable to talk about dying and death. Now a constituted community association, Finity has developed and run a variety of arts and information events in the local community. As part of this, Jo worked together with Pippa Stevens (an executive coach) and Sue Raynsford (a business process consultant) to develop and run a series of workshops. These workshops covered topics about dying, death and loss, and how we can make plans in advance. The aims were to give participants information, vocabulary and a chance to discuss these issues, with encouragement to start planning for the end of life. The successful pilot series was run in 2014.

#### What is in this manual?

Each chapter is a 'recipe' to run a workshop session with specified main aims, the topics to cover, timings, suggested specialists to invite, the format and possible alternatives, briefs for specialist speakers and hand outs. There are some similarities between the various workshops, with some identical aspects in each, such as the housekeeping and ground rules. Please note that the manual and its references are written from a UK-based point of view but wherever you read the manual it will be useful.

This facilitators' manual has been developed so that you can run your own series of workshops in your community. It can be used in full or as a framework to be adapted to the needs of your community and the specialists you have available. It was important to make everyone feel safe during the workshops.

It is important to emphasise the need for mutual respect between all those who are present, so that ideas and concerns can be explored and shared freely. Weekly evening sessions were run and specialist guest speakers were asked to appropriate workshop sessions. Each session focused on a specific topic. Some sessions were blended, for example the preparatory session with workshop 1. The facilitator can lead any of the sessions if they feel confident in delivering the information, some of which needs specialist knowledge (for example, legal issues).

This manual is intended to be simply a guide. You could run the sessions on an ad hoc basis, once a month, or together in one or two days. Participants could be encouraged to attend all of the workshops or each could be tailored to meet the needs of a specific group within the community. Please use the guide freely to suit your own situation. Finity ask that it is not used for any financial gain. The guide is available free as a download or hard copies for a small charge.

**Contact** [info@finito.org.uk](mailto:info@finito.org.uk) for further information.

**The Conversation Game** and **The Circle of Life Board Game** offer resources (2 and 3) that can be embedded into learning and development and support new facilitators for very little cost.

### **Resource 2 - The Conversation Game**

The game offers a great tool to facilitate discussions, getting people to think and talk about positive values and goals for having the best end of life possible.

Who can benefit from using the game?

- Social workers, health educators, and care home staff and anyone meeting with patients and their loved ones to start conversations about end of life care.
- Hospice workers to stimulate discussions about what the patient may hope for.
- Physicians can use the game with a patient who doesn't have anyone to act on their behalf, to give them a chance to understand what goals and values are guiding the treatment decisions the patient is making.
- A patient to help them articulate their priorities and concerns.

- A mother, daughter, father, sister, brother (healthy or ill) who wants to open the conversation with partner, parent, family member or friend.
- In health education classes on advance care planning to help patients and their potential advocate compare and discuss priorities that they hold in common, and to discover where their priorities differ.
- Community members in community meetings, at family gatherings and in religious discussion groups.
- Individuals with elderly parents or young adult children to help prepare for their possible role as health care spokesperson.

**Individuals** who have **mild dementia** or those with **poor eyesight** can participate in the game by expressing how much they agree with the statement on each card when they are read aloud. Those with higher intellectual capability use the statements on the cards as discussion starters on the various meanings and implications of the statements and when they might agree or disagree.

### **How does the game work?**

The game is a set of 36 cards, each card with a short statement of things people often cite as being important to them in the last weeks or months of life. The instruction leaflet for the game gives other ways to play it in pairs or groups. The point of the game is not to create a written list of “what I want,” but to stimulate conversations about what is important and why.

**Mary Matthiesen, Director, the Conversations for Life Programme -**  
[www.conversationsforlife.co.uk](http://www.conversationsforlife.co.uk)

### **Resource 3 – The Circle of Life Board Game**

The Circle of Life Board Game is designed as a training resource to support learning and consolidation of knowledge in end of life education. Each Game covers four topics, two of which remain constant themes, Communication and Advance Care Planning. There are six other subject headings that can be chosen as optional topics that form the four topics of the game (these can also be viewed via the slide show):

- Assessment
- Bereavement
- Cultural considerations
- Last days of Life
- Managing symptoms
- Spirituality

The board game is an ideal training engagement activity as it meets all learner needs (Kinetic, Visual, Audio and Reading (Theory)) and takes away the emphasis of “learning” as you are in fact “playing a game”. It subtly allows each learner to be involved and learn in a fun and humorous way. The “Trainer” leads the game and “teams” play rather than individuals answering the questions. This is an important factor as it promotes a supportive non-threatening learning environment and encourages communication and small group working. Throughout the activity, the Trainer is able to assess the amount of learning that has taken place by observing the group and the individuals within it.

The Board Game can be used with all members of the Multi-Disciplinary Team (including GPs, Consultants, trained Nurses Housekeepers, Chefs, and Care Assistants etc.) within all care settings. Any leftover cards when the game is finished can be used for further learning on a particular aspect of a training need outlined in the intended Learning Outcomes.

The Board Game promotes active participation from all types of learners, encourages discussion and debate in a fun and supportive environment. It supports team building and allows even a less confident learner to feel more assured about their own abilities as it is a shared process and everyone has had equal opportunity to participate. The philosophy of the Board design is the representation of the four seasons with a stone path working its way through the year. The path is formed as a loop to demonstrate the “circle of life” through the seasons, with the tree symbolising life itself. [www.intheendcare.org.uk](http://www.intheendcare.org.uk)

## Sample asset mapping template

**Description of the common goal** - To provide sector wide resources and training activities to encourage people to talk about death and dying, including staff who may engage with people who are dying or their families as part of their role.

Category – Individual/ Organisation/ Groups & Networks	Asset	Resource description	Availability / Accessibility	Existing connections	Added value
Individual	Jane Smith – employed at Hope Hospital Trust, Rutvon.	EoLC Facilitator and trainer specialising in communication skills training and MCA.	Limited to 15-mile radius of base. Available average max of one session a week.	Local lead of the national EoLC Facilitators and Champions Group.	Main focus on prof. training but also inputs to workshop sessions in the community as part of Dying Matters activities.
Individual	John Jones	Expert patient volunteer using own experience to support community activities.	Works full time but can be available with plenty of prior notice.	Member of Dying Matters Coalition. Local volunteers network. Works with St Gwyneth Hospice.	Experienced in leading workshops and speaking at large community events.
Organisation	St. Gwyneth Hospice – current host/lead organisation	Existing training resource centre. Existing communication skills training Resources/ trainers. Fund raising expertise.	0.1 FTE of coordinator time available during three-month development phase. Potentially one session a week of trainer's time. Training rooms.	Links/ networks across sectors. High profile in local community. Strong links with education providers. Members of DM.	St. Gwyneth has a track record of putting staff forward to contribute to national projects and activities and has national reputation for innovation.
Organisation	HEE local office	Provide access and linkages to national work and networks. May be able to identify seed funding opportunities.	Available for steering group.	National links.	Ability to see wider picture to avoid duplication.
Groups and Networks	Rutvon Cruse Bereavement Care	Locally based counsellors specialising in bereavement care.	Available with notice for steering group.	Part of a national organisation.	Already provides national training developed by Cruse.
Groups and Networks	Rutvon Volunteers Network	Provide examples of experiences either of themselves or others close to them. Contribute to training and sense check.	Available with notice for steering group and supporting activity delivery.	Links across health and care where volunteers are part of end of life care.	Many are used to running workshops and speaking to large groups.



# Part Two – The Detail

## Introduction

Every professional needs to be competent and up to date in the knowledge and practice that enable them to play their part in good end of life care. It is vital that every locality and every profession has a framework for their education, training and continuing professional development, to achieve and maintain this competence. That framework must allow expertise and professionalism to flourish in the culture of every organisation and every caring contact. It should offer practical examples of how care can be delivered in a way that is tailored to the person. If our ambitions are to be achieved there must be a consistent and common use of such educational resources for palliative and end of life care. The Local Education and Training Boards must support educational and service providers to use to their full potential the opportunities for learning and development that exist locally, and where needed to develop new opportunities.

***Ambitions for Palliative and End of Life Care:  
A national framework for local action 2015-2020***

Health Education England (HEE) commissioned the National Council for Palliative Care (NCPC) early in 2016 to undertake a project to look at a variety of different and new ways to build a more sustainable asset based approach to end of life care workforce learning and development.

End of Life Care (EoLC) cuts across specialisms, settings (hospital, care home, community and hospice), workforces (medical, nursing, AHPs, social workers, community health and care staff, generalists, specialist and many others including an increasing number of trained volunteers) and geographies. Since the 2008 End of Life Care strategy considerable work has been undertaken in developing the strong links between sectors and settings around workforce learning and development, which has raised challenges including overcoming the differences in funding. Formalised partnership working to reflect local decision making and delivery has developed and continues to do so, and it should be recognised that historically those involved in end of life care have always given generously of their time and energies to support the development of others across sectors.

## Context

This project sits as part of several work streams that help HEE fulfil its requirements in terms of the Choice Commitment (*Choice in end of life care: government response – DH July 2016*) and as a member of the **Ambitions for Palliative & End of Life Care Partnership**. For more information visit the website [www.endoflifecareambitions.org.uk](http://www.endoflifecareambitions.org.uk).

The 'Ambitions for Palliative and End of Life Care' framework highlighted the need to focus on local decision making and delivery at a time of constrained resources and increasing demand which necessitates putting existing resources to more creative and effective use. Health and social care are equal partners in achieving new ways of working and an asset based approach within communities is a way of being creative and effective. Within a learning community it will also include working with a potential wider range of partners including local education and training providers.

## Project objectives and methodology

### Project objectives

- Explore what does and does not work in existing asset based approaches in learning and development for end of life care workforce, and identify the conditions for it to work.
- Identify what evaluation of asset based learning and development has taken place or is possible.
- Look at what more general asset based approaches have achieved e.g. Dying Matters, Dementia Friends, Compassionate Cities and others.
- Collate examples of good practice in asset based learning and development in end of life care to share and build on the learning.
- Identify what factors are needed to enable asset based approaches in end of life care learning and development to be scaled up and rolled out more quickly.

## Project methodology

### a) Desk top research phase

- A literature overview to explore more general asset based approaches to see what works, what has been achieved and the learning to be shared.
- Review work already undertaken by HEE and others related to the future of end of life care learning and development to identify key themes for the review phase in-depth exploration.
- Use NCPC and Dying Matters' own assets (networks and intelligence) to gather initial feedback on what is happening locally.
- Draft a discussion template for agreement with the HEE central team to be used with the five HEE local areas to gain additional information.

### b) Review phase

- Using the agreed discussion template to work with the five HEE local areas to gather additional information and case studies. The local teams will have prior sight of the template and completion will be undertaken either by phone, personal visit or small local workshop – it is not intended to add to the local teams' workload by asking them to complete the template prior to the meeting/call unless they wish to.

The local areas are:

- Dorset
- Thames Valley
- North West
- Birmingham
- London

- Using NCPD and Dying Matters assets (networks and intelligence) to gather in-depth feedback and case studies on what is happening in each of the five areas related to workforce development activities in end of life care including asset based approaches and others i.e. models of joint development and sharing across sectors including charities and social care, where links and activities work well and where challenges exist.
- Analyse case studies to identify key factors for success and identify learning.
- Undertake a thematic review from all information gathered.

## Limitations

The expectation at the start of the project was that people understood what an asset based approach meant, if not around learning then possibly across health and social care more generally. This was not the case and considerable time was needed to discuss the approach and to then identify any local activities that could be usefully included. This resulted in multiple contacts having to be made, thereby extending the review period.

Recent organisational changes have resulted in intelligence and opportunities for local networking being lost in some areas, as well as key people moving on. Local HEE areas where a strong end of life network has continued could offer useful information, but many of the local HEE's are still at the stage of planning or undertaking information gathering exercises around what is happening in their areas as well as creating new networks. Therefore, information available for the project was limited and a decision was made to widen the contacts and networks that NCPD had originally identified in the search for usable case studies. Annex 2 contains a full list of contributors to the project, however this does not reflect the total number of people who were contacted via networks facilitated by some of the contributors on the list. It is thought that a lack of understanding of an asset based approach could contribute to the low number of responses received as well as considerable time pressures those in end of life services are experiencing.

As a response to a wider call for examples, resulting in more in depth discussions, it became apparent that whilst offering excellent examples of partnership working across sectors and communities the methodology could not really be described as having an asset based approach as used for the purposes of this report. Many had to be discounted thereby reducing the numbers of usable examples.

This has resulted in a reduced number of examples to analyse and more reliance has been made on the research and learning from recognised asset based methodology more generally, which has been adapted where appropriate to provide the guidance set out in Part One. Sense checking events will be undertaken as part of a wider activity planned by HEE on completion of the report.

## Learning communities

Identifying a community working towards a common goal, establish sustainable connectivity, and to share and exchange assets to achieve that goal is the foundation of an asset based approach.

Recently two reports have been produced which look at community development in relation to end of life care and describe more fully the public health approach which aims to enhance all supportive networks as well as encompassing professional ones. Although not specifically relating to learning communities they provide useful insight and background.

They are:

- *Each Community is Prepared to Help: Community Development in End of Life Care – Guidance on Ambition Six (2016)*. This guidance provides a theoretical framework and gives practical examples of how different health and social care organisations can start to use community development as a routine part of their provision of end of life care.
- *Dying Well Community Charter Pathfinder Project – Evaluation Report (2016)* – this provides examples in differing settings of how this implementation takes place and describes some of the early benefits of doing so.

Both provide more detail on the ‘Dying Well Community Charter’ which focuses on underlying principles, and the ‘Compassionate City Charter and Toolkit’ which looks more at the ‘what and where’ practical capacity building examples.

The evaluation of the pathfinder project includes lessons learnt, and some of these can be adapted for those developing an asset based approach within learning communities.

Those adapted for this project are:

- Whilst enthusiasm and commitment can be high from individuals and groups it is important to ensure sustainability that it is embedded within organisational strategies.

- The principles of partnership, working across sectors is well known, however knowledge and understanding of a community based approaches is limited.
- Keep it simple – one size does not fit all.
- Develop a team approach to reduce dependency on an individual lead.
- It is not a quick fix and developing a community-based approach should be a long-term project to change culture and attitudes.

The advent of general asset based approaches seen in the Compassionate Cities Charter, the Dying Matters Coalition and Dementia Friends has opened up greater collaborative working opportunities to hold events and run joint raising awareness campaigns to benefit those delivering and receiving end of life care.

(See separate sections for more on the Dying Matters Coalition and Dementia Friends).

## What is an asset based approach

*The conceptual and practical foundations of asset based working are not necessarily easily understood by those new to this field. Even among practitioners whose work reflects or is guided by many aspects of asset based practice, it is often more an intuitive sense of what is right that drives their work than a detailed grounding in the theoretical foundations of this field.*

***Heads, hands and heart: asset based approaches in healthcare – The Heart Foundation (2015)***

The purpose of this guide is not to provide a detailed review of literature and evidence underpinning an asset based approach in general, but to give an insight into what it means and how it can be adapted for learning communities. The following paragraphs provide limited background but signpost to the more detailed work available.

When reading the existing work around asset based approaches within health care it becomes evident that much of the methodology and principles can be adapted to the approach needed for learning communities as described within the scope of this project.

The Health Foundation in their 2015 research into asset based approaches in health care offer a theory of change model with the following key components:

- **Reframing thinking, goals and outcomes** - Exposure to underpinning ideas, reassessment of current practice and priorities towards asset based working, and the identification of champions to drive change.
- **Recognising the assets available to achieve the change** - Mapping and describing the individual, organisational, associational, economic, cultural and physical resources available to communities.
- **Mobilising assets for a purpose** - Understanding and agreeing how community assets can be connected and used. New relationships, new approaches to leadership, systemic action across organisational boundaries.
- **Co-producing outcomes – on the pathway to the long-term goal** - Co-production of services and outcomes by professionals and citizens. The coming together of equals, each with assets and strengths, around a common goal or a joint venture.

*The asset approach values the capacity, skills, knowledge, connections and potential in a community. It doesn't only see the problems that need fixing and the gaps that need filling. In an asset approach, the glass is half-full rather than half-empty. The more familiar 'deficit' approach focuses on the problems, needs and deficiencies in a community.*

***A glass half-full: how an asset approach can improve community health and well-being - I&DeA (2010)***

The following table shows the differences between a ‘deficit’ and ‘asset’ based approach in health communities:

Moving from a deficit approach to an asset approach	
Where we are now – the deficit approach	Where an asset way of thinking takes us
Start with deficiencies and needs in the community	Start with the assets in the community
Respond to problems	Identify opportunities and strengths
Provide services to users	Invest in people as citizens
Emphasise the role of agencies	Emphasise the role of civil society
Focus on individuals	Focus on communities/neighbourhoods and the common good
See people as clients and consumers receiving services	See people as citizens and co-producers with something to offer
Treat people as passive and done-to	Help people to take control of their lives
‘Fix people’	Support people to develop their potential
Implement programmes as the answer	See people as the answer

## The Asset Based Community Development Approach (ABCD)

ABCD builds on the assets that are already found in the community and mobilises individuals, associations, and institutions to come together to build on their assets - not concentrate on their needs. An extensive period is spent in identifying the assets of individuals, associations, and then institutions before they are mobilised to work together to build on the identified assets of all involved. Then the identified assets from an individual are matched with people or groups who have an interest or need in that asset. The key is to begin to use what is already in the community. The ABCD Institute [www.abcdinstitute.org](http://www.abcdinstitute.org) provides more information and a toolkit.

The ABCD Institute categorises assets and inventories into five groups:

### **Individuals**

At the centre of ABCD are residents of the community that have gifts and skills. Everyone has assets and gifts. Individual gifts and assets need to be recognized and identified. In community development, you cannot do anything with people's needs, only their assets. Deficits or needs are only useful to institutions.

### **Associations**

Small informal groups of people, such as clubs, working with a common interest as volunteers are called associations in ABCD and are critical to community mobilisation. They don't control anything; they are just coming together around a common interest by their individual choice.

### **Institutions**

Paid groups of people who generally are professionals who are structurally organised are called institutions. They include government agencies and private business, as well as schools, etc. They can all be valuable resources. The assets of these institutions help the community capture valuable resources and establish a sense of civic responsibility.

### **Physical assets**

Physical assets such as land, buildings, space, and funds are other assets that can be used.

### **Connections**

There must be an exchange between people sharing their assets by bartering, etc. These connections are made by people who are connectors. It takes time to find out about individuals; this is normally done through building relationships with individual by individual.

## Asset based approaches in a health and well-being context

The Realising the Value Consortium in its 2016 report provides useful information around asset based approaches in a health and wellbeing context, and describes its aim to promote and strengthen the factors that support good health and wellbeing, protect against poor health and foster communities and networks that sustain health. The vision is to improve people's life chances by focusing on what improves their health and wellbeing and reduces preventable health inequalities.

Their work describes asset based approaches as having a different starting point to traditional health and care services. Fundamentally, the approach asks the question 'what makes us healthy?', rather than the deficit-based question 'what makes us ill?' These approaches are based on creating and sustaining broadly based support in the community outside of the traditional boundaries of health and social care services, to promote good health and wellbeing, and strong social connections. An asset based approach takes account of how people live and how they can be enabled to realise their potential, as well as the things that matter to them in all spheres of life, not just physical and mental health.

*A theme to emerge from the consortium's research at the time was the potential tension between asset based approaches and professional identity and ways of working among health care professionals. They mention that published case studies also show that some people struggle with the new model, as it is not the model of care they expect from the health services. This implies that training and support for both professionals and people will be required for asset based community development to be implemented at scale.*

## Partnership and community activities that can be a foundation for an asset based approach

Partnership working to deliver end of life care services often include sharing of resources and the giving of time from key people which has led to innovative developments to improve services across sectors, but the terminology of 'an asset based approach' is not often familiar.

The following case studies offer some excellent examples of partnerships that bring an end of life community together, and whilst not focussed primarily on an asset based approach to learning it is likely that elements of their work would include the approach described in this report and where an asset based approach to learning could be more widely integrated given the connectivity already established.

## Case Study 14 - Wirral Citizens Charter

With its set of 12 expectations, the Charter promises 'care, kindness and understanding for people at the end of life'. It seeks to show that help is available for people with life-limiting conditions to have the best quality of life possible, for as long as possible, and that their wishes lie at the heart of their end of life care. The Online Resource has been launched in support of the Charter and its ideals. This Resource is designed to help everyone, from those seeking information about the end of life care services available on Wirral to professionals wishing to access guidance and advice.

**The Online Resource** – It is a comprehensive reference resource for end of life care available in Wirral for professionals and the general public. It is designed to underpin the values set out in the Wirral End of Life Care Charter, which calls for care, kindness and understanding for all facing the challenges of end of life care, be they patients, their families and carers, or professionals.

The activity started in 2014 and launched in May 2015. It is hosted by Wirral St Johns Hospice on behalf of the Wirral Palliative and End of Life Care Partnership Group. Involved in the development and on going evolution of the charter are the local acute Trust, Community Trust, CCG, Public Health Wirral Council, a number of GPs, care homes, and the older people's parliament. Also 126 individuals have added their commitment. The activity is targeted at all care settings, all professionals and the whole community and built on the Cheshire and Merseyside charter, originally developed through the network education group. The main challenge has been time and leadership. Momentum is kept up through the governance through the partnership group.

[www.endoflifecarewirral.org](http://www.endoflifecarewirral.org)

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## Case Study 15 - Challenges in End of Life Care – Harrow and NW London

As part of a HENWL sponsored project: Educating the Primary Care workforce to perform Anticipatory Care Planning, the project has delivered education between December 2014 and April 2015, to 325 health care professionals, 249 of whom have been GPs or GP registrars. The focus of the education program had been on communication skills, legal and ethical aspects of end of life care, prognostication (identifying those in the last year of their life) and prescribing for palliative care patients. These were developed as the 'core curriculum' topics. The model recognised the value of planning and delivering learning jointly by experienced GPs and a multi-professional faculty of specialists (doctors, clinical nurse specialists, pharmacists and social workers). The project has been extremely successful, with feedback being overwhelmingly positive and in order to continue with the momentum, a programme for a further year of education was developed. An additional 223 health professionals have been educated during the 11 training sessions between October 2015 and March 2016.

Within the first year, there had been such demand that it was extended to open the sessions to Brent GPs and other multidisciplinary professionals such as District and Practice Nurses, London Ambulance Service paramedics, pharmacists and Health Care Assistants. The aims of the second phase were to widen the geographical reach of the education, refine the delivery of the existing core curriculum sessions and create new disease specific sessions to contextualize this core curriculum and keep up interest and attendance. In addition, other aims included exploration of RCGP accreditation of the programme as well as expanding the training to cover the Harrow Enhanced Practice Nursing Project and nurses/carers in care homes.

During 2014 - 15 the Harrow Community Education Provider Network Project, an end of life care training programme for Band 1 - 4 carers in care homes in Brent and Harrow was set up. This has also been very successful and has trained and supported 16 'End of Life Champions' (EOLC) in 12 care homes. Phase two of this project was incorporated within the Challenges in End of Life Care Project and aimed to continue supporting the current care homes and end of life care champions with reflective practice sessions and extend to a further 8-10 care homes. At present 14 'End of Life Champions' places have been allocated.

### Reasons for success:

1. Dedicated project team. Although now hosted in a hospice, this team is managed and lead by a GP supported by a palliative care consultant.

2. Essential and very strong linkages to primary care through the Macmillan GP lead. This is vital in keeping the training very focused on the needs of GPs and the local health community professionals and ensures close links between training and service development and improvement.

3. Wide training faculty.

4. Open to emergent ideas and learning as we go.

5. Used a variety of teaching opportunities: Weekends, afternoons, evenings and off site, in surgeries or in hospital or hospice sites.

6. Each session is led by a GP alongside a specialist- Usually a palliative care professional but sessions have been co-delivered by Geriatrician, psychogeriatrician, ethicist, ITU consultant, respiratory specialist Physio, pharmacist etc.

7. Varied content.

8. Most effective utilisation of local expertise by sharing out the burden of training and maximising publicity through shared media.

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### Case Study 16 - Royal Trinity Hospice

Offer regular workshops available to their own staff/volunteers as well as the wider health and social care communities on:

- Communication skills to help those in distress (Sage & Thyme).
- Holistic care at the end of life (including verification death and bereavement, Priorities of Care).
- Symptom control in last days' life including syringe pump training.

They run 'Quality End of Life Care for All' (QELCA) training in response to requests i.e. empowering teams to make a difference to the experience of dying patients and those close to them and they offer secondments, Goldfish Bowl techniques, shadowing and training places for most professionals, including return to practice.

They have engaged with Wandsworth CEPN in developing a workshop for Practice Nurses on EOLC (currently no plans to repeat), and are part of the South London Hospice Education Collaborative set up to strengthen the voice with HESL. This has helped support QELCA and practice nurse workshops.

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### Case Study 17 – St Richard’s Hospice

As a community nurse specialist team, they often received requests for students ‘to come out for the day’. Learning requirements were often unclear, some students clearly saw this as a day out and were not particularly interested in the work of the hospice, whilst some became extremely distressed (despite the team’s best planning to ensure patients were suitable for student nurses to see). For the team this was causing lots of concern, their time is pressured and they wanted to offer a useful learning opportunity to those students who were interested. They knew Worcester University’s standalone palliative module had been phased out and some students were saying they desperately wanted more exposure to specialist palliative care. The team also wanted to minimise distress by having advance notice if the student had experienced a bereavement. The team therefore approached the university and developed a bespoke palliative care education initiative.

They target student nurses from all disciplines at the end of year two and beginning of year three. They offer the programme twice a year for a maximum of 16 students. The university lecturer they worked with emails out to the appropriate cohorts of students and asks them to give 250 words explaining why they want to attend. They are also asked if they have had any recent bereavements.

#### **The programme developed aims to:**

1. Ensure the students actually enter a hospice building.
2. Identify their own key learning needs.
3. Provide bespoke MDT education in response to identified needs. This gives the group direct access to a palliative consultant who will answer their questions, a senior counsellor who will give tips on talking to patients, difficult questions, working with children and chaplaincy who talk about spirituality (in all its forms).

4. Offer the ability to undertake a clinical placement – all areas within the hospice offer dates when they can accommodate a student. The students then book into the date and department which best suits their needs. They can access a minimum of 1 clinical day placement. Placements include chaplaincy, community consultant, in patient unit, day hospice, counselling, children's services, community services.
5. Enable students to apply their learning to patient's scenarios.
6. Develop self-care skills - this is something the students say they get very little practical help with. This session is delivered by the hospice psychologist.
7. Raise the questions they have been too afraid to ask so far in a supportive and specialist environment. Every group wants tips in how to answer the question 'Am I dying?'

Once established the hospice actually requires very little additional resources. All team members are signed up to the value of this project. All case studies are in place. There is limited admin required now each time it is offered. It does need a minimum of one nurse specialist available for each taught day. The programme is very sustainable and transferable. It has now been developed on from this and not only offers this programme twice a year but also offers full student placements for adult and mental health students. Mental health students were particularly desperate for information to support their patients at end of life and this has spurred the hospice on to offer a full mental health placement. It took time to find the right University lecturer who could see the benefits and was willing to work with the hospice team and invest their time.

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## The Dying Matters Coalition

The Dying Matters Coalition (DM) as an entity could be argued to use an asset based approach to achieving positive change. It combines human, social and physical assets to collectively create a positive change to the end of life experience and to bereavement support. It facilitates people and local communities coming together to achieve change using their own knowledge, skills and personal experience. Learning communities will include members of end of life care networks, and many will already be engaged in Dying Matters activities and they collectively become an asset by being able to adapt the learning from bringing people and communities together for Dying Matters to take forward the same approach for workforce learning and development. The case study detailing the 'Pushing up Daisies' festival won the Dying Matters Awareness Initiative of the Year in 2016 and demonstrates what can be achieved with very little funding and mobilisation of existing assets to deliver an activity.

### Case Study 18 - Pushing Up Daisies Festival

This was an eight-day 'festival' in May 2015 to encourage people in the town of Todmorden (West Yorkshire) to think about, and talk to each other about, death and dying. The festival was called 'Pushing up Daisies' and it was described as being: 'organised by a group of Todmorden folk who find thinking about, talking about and planning for death pretty scary. We'd like it to be easier, kinder, more communal, less frightening. And not just in the hands of professionals: more in our own hands too. So, we got together, invited the rest of the town, and have come up with this Festival.' The focus was simply that anything could be included so long as it helped folk to talk together about death and dying. This Festival was innovative in so many ways.

#### Here are just some:

- It was run by a large number of volunteers.
- It included film, theatre, dance, music, talks, art, poetry, storytelling, exhibitions, therapeutic groups and community activities.
- It included thinking about cultural differences from around the world.
- At least 18 venues across this small town took part.
- There was no funding and almost all events were free.

Many of the events were ideas from the growing network of volunteers, events were developed only for this festival, so many of them must have been original. The three people who initiated the Festival discussed some initial ideas for an event to be held over a weekend in the Unitarian Church. The idea of running a community event about death and dying had come about as a result of their 'Death Doula' or End of Life Companion training. Each of those three then sounded out a few other local people to check that others felt an event of this nature would be acceptable to local people. Volunteers from a community-based organisation called 'Incredible Edible Todmorden' were consulted as well as the managers of a couple of restaurants considered as possible venues. Soon everyone was buzzing with ideas and offering to do things. The programme began to grow and soon developed into an eight-day long festival, taking place in venues all over town. Even after the programme was printed, new people came on board with additional events, because so many wanted to contribute something. The event was run entirely by volunteers and without funding – the costs of materials were met by the volunteers themselves. The festival was community-led and people offered their expertise out of kindness. This meant it was almost all free and there was such a range of events that both young and old took part.

**Benefits** - This was the first time Todmorden has ever held an event like this. Because there were no funders, there was no formal evaluation, but the event was successful because:

- Hundreds of people attended.
- Sessions had enough people attending to make them worth running (despite foul weather at the start of the week).
- Some of the sessions were deeply personal and yet many people felt safe talking about their grief there, and commented that they found it very helpful to be able to admit their grief in public.
- 'Listeners' were available throughout the week and some people took great comfort from a kind listening ear.
- People of all ages and backgrounds took part and there was something for everyone in the events provided.
- Some felt strongly that the Festival opened a discussion that needed to be continued.

- Two spin-off groups – one for people affected by suicide and another called the ‘Good Grief’ group – were set up as a result of the Festival and continue to meet regularly, enabling people to share grief and offer support to each other.
- People have talked about the Festival for months afterwards.

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The support and resources provided by Dying Matters for people and communities to come together, and some of the activities undertaken, can be seen in more detail through the following links:

- Through awareness-raising events, both DM and by sharing and promoting external organisations’ events:  
[www.dyingmatters.org/node/add/shared-event](http://www.dyingmatters.org/node/add/shared-event)
- By providing information and advice on hosting a Dying Matters event, both DM and through supporter case studies:  
[www.dyingmatters.org/page/top-tips-organising-your-event](http://www.dyingmatters.org/page/top-tips-organising-your-event)
- By running an annual national awareness raising week, calling on coalition members, supporters, communities, interested bodies, partner organisations – affiliated and non-affiliated – the government and the general public to support and promote the cause of better end of life care and bereavement support for all:  
[www.dyingmatters.org/slide/dying-matters-awareness-week-launch](http://www.dyingmatters.org/slide/dying-matters-awareness-week-launch)  
[www.dyingmatters.org/BigConversationlaunch](http://www.dyingmatters.org/BigConversationlaunch)
- Through communications training for GPs and other health and social care professionals: [www.dyingmatters.org/page/gp-training-dvds](http://www.dyingmatters.org/page/gp-training-dvds)
- Via the DM website community area, which includes forums where people can share knowledge or opinions and ask for advice:  
[www.dyingmatters.org/forum](http://www.dyingmatters.org/forum)
- Via the DM website tool, Your Stories, through which users can share their personal experiences of good and bad end of life care:  
[www.dyingmatters.org/stories](http://www.dyingmatters.org/stories)

- Through My Funeral Wishes – a free funeral planning resource offering people the opportunity to make their wishes known to loved ones:  
[www.dyingmatters.org/page/my-funeral-wishes](http://www.dyingmatters.org/page/my-funeral-wishes)
- Through blogs from external individuals and organisations, in which they can discuss their own experiences or share their work in end of life care or bereavement: [www.dyingmatters.org/blog](http://www.dyingmatters.org/blog)
- Through the Find Me Help directory, which provides free information on national and local non-commercial support for those approaching the end of life or those caring for them; it is also free to organisations to sign up:  
[www.help.dyingmatters.org](http://www.help.dyingmatters.org)
- Via a range of resources, some of which are co-brandable, including: films, leaflets, publications, postcards and posters, presentations:  
[www.dyingmatters.org/overview/resources](http://www.dyingmatters.org/overview/resources)
- Through the School Lesson Plan, to help prompt students and teachers to think and talk about death, dying and bereavement:  
[www.dyingmatters.org/page/SchoolLessonPlan](http://www.dyingmatters.org/page/SchoolLessonPlan)
- Via the find your 1% campaign, a mobilising call to action supporting GPs and other health care professionals in delivering good quality EOLC:  
[www.dyingmatters.org/gp](http://www.dyingmatters.org/gp)
- Via the informative website content, which includes invaluable (and perennially popular features) information around subjects including ‘Being with someone when they die’, ‘Telling someone about a death’ and ‘Signs that someone is dying’:  
[www.dyingmatters.org/overview/need-support](http://www.dyingmatters.org/overview/need-support)
- Through the provision of regular newsletters to subscribers:  
[www.us2.campaign-archive1.com/?u=ea6a78606131cd2a0c50cb52b&id=d6405502be&e=555f376a11](http://www.us2.campaign-archive1.com/?u=ea6a78606131cd2a0c50cb52b&id=d6405502be&e=555f376a11)

## Dementia Friends

The Alzheimer's Society's Dementia Friends programme is the biggest ever initiative to change people's perceptions of dementia. It aims to transform the way the nation thinks, acts and talks about the condition.

To support learning and development for end of life health and care staff Dementia Friends can be regarded as an important asset offering a number of resources. Declining ability to communicate characterises the later stages of dementia, and health and care staff at all levels should be trained to provide high-quality, person-centred care to improve dignity and quality of life even when communication has diminished.

A Dementia Friends Champion is a volunteer who encourages others to make a positive difference to people living with dementia in their community. They do this by giving them information about the personal impact of dementia, and what they can do to help. The Dementia Friends team works with all types of organisations from large to small across the private, public and third sector. Their job is to support organisations with a successful rollout of Dementia Friends to their workforce.

Ways that an organisation can get involved:

- The organisation can sign up and access the videos and other relevant resources.
- They can embed the Dementia Friends videos in to the local intranet/e-learning platform for staff to engage with.
- Arrange for staff to attend a Dementia Friends Champion volunteer induction day and learn how to deliver Information Sessions to their colleagues. For example, in team meetings or lunch and learns.

Since its introduction, Dementia Friends have gained a good understanding of what works well and they can provide resources and helpful tips for communicating with and engaging staff. The following are case studies extracted from the Dementia Friends website [www.dementiafriends.org.uk](http://www.dementiafriends.org.uk).

## Case Study 19 - Lewisham and Greenwich NHS Trust

Lewisham and Greenwich NHS Trust began providing Dementia Friends Information Sessions to staff in April 2014. Awareness was raised by showing the Dementia Friends videos via iPads at staff meetings, shift hand overs and study days. There was also the option of 45 minute sessions which were delivered by the Trust Dementia leads in the education centre. The week was a great success having exceeded the target with 1268 staff becoming Dementia Friends.

Mark Johns from **North East Ambulance Service (NEAS)** writes:

*'North East Ambulance Service has signed up to the Dementia Friends initiative in May 2015 as part of our work around Dementia Awareness Week. The profile of our service users indicates that older people (60+) use our services more than other groups and as dementia can impact on older people more we felt it was important that staff have a good understanding of this issues and how we can support people with dementia. Our CEO has committed to ensuring the Trust (North East Ambulance Service NHS Foundation Trust) trains every employee in the 2016/17 financial year. This will be facilitated through using Alzheimer's Society's Dementia Friends resources and backed up with a bespoke resource developed by North East Ambulance Service. To date we have trained over 300 people, issuing each member of staff with their Dementia Friends badge, giving them a copy of the NEAS pocket handbook and Alzheimer's Society publications. We have trained eight staff to become Dementia Friends Champions and we have a number of other people lined up to support with this role.'*

**Central Bedfordshire Council's** involvement in Dementia Friends began in September 2014. The Council's Chief Executive gave all council officers the opportunity to become Dementia Friends. They have organised four information sessions to be run at their offices as well as having had a number of staff go on to train as Dementia Friends Champions. They have found that the Information Sessions have highlighted the amount of people touched by dementia in immediate family or friends. They are also promoting the development of Dementia Friendly Communities in their area supporting local people to become Dementia Friends. [www.dementiafriends.org.uk](http://www.dementiafriends.org.uk)

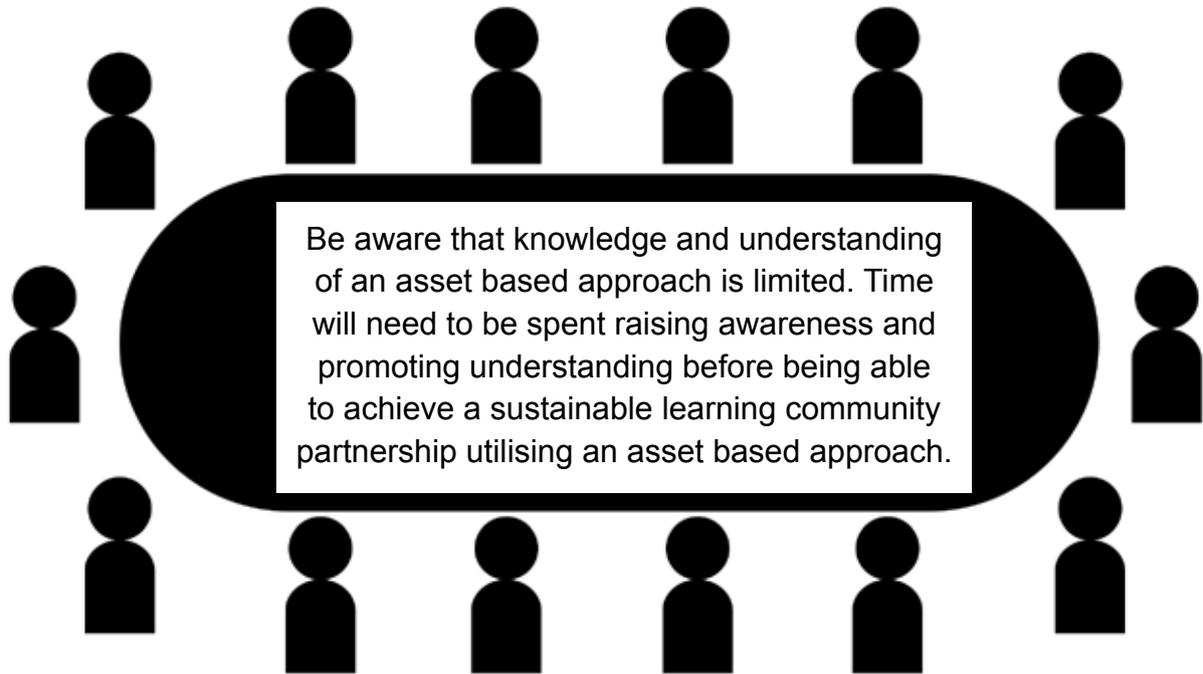
## **The Alzheimer's Society's supporting undergraduate nurse education**

In March 2016, an evaluation was published of a project undertaken in Northern Ireland to deliver a two-hour 'Dementia Friendly Community (DFC) Workshop' written by the Alzheimer's Society, to an entire cohort of first-year undergraduate nursing students in one Higher Education Institution. Following delivery of the programme, students were asked to complete a short questionnaire on their knowledge and confidence in relation to dementia care before and after the Dementia Friendly Community programme. A total of 322 undergraduate first-year nursing students took part in the programme. Of these, 304 returned questionnaires; 31.25% of students stated their perceived improvement in dementia knowledge was 'good' while 49.01% stated their perceived improvement in dementia knowledge was 'very good' and 13.49% stated their perceived improvement in dementia knowledge was 'excellent'. In relation to confidence in engaging with people with dementia, 31.91% stated 'good' improvement, 40.79% stated 'very good' improvement and 11.84% stated 'excellent' improvement. The undergraduate students positively reviewed the Dementia Friendly Community programme as it enhanced knowledge and confidence in relation to care of someone living with dementia. The full article can be accessed by the link in Annex 1.

The evaluation concluded:

The delivery of a two-hour DFC programme, which was designed by the Alzheimer's Society, increased first-year nursing students' knowledge about dementia as well as their confidence in communication and engagement of people living with dementia. Given the current drive for 'dementia-friendly' communities, which include clinical practice, the DFC programme offers an opportunity for undergraduate nursing students to increase their knowledge and confidence in dementia care. The Alzheimer Society Champions are experienced, trained volunteers who deliver the programme for no formal cost and considering this, coupled with the findings of this paper, the 'dementia friends' programme should be recommended as an integral part of any undergraduate nursing programme.

**Extract from 'Evaluation of 'Dementia Friends' programme for undergraduate nursing students: Innovative practice (2016)**



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