



National Association for Hospice at Home

June 2019

So Summer has arrived at last and along with the sunshine, comes our quarterly newsletter. We hope you are enjoying our newsletters and as always, we are keen to hear your feedback in terms of what you like, how we could improve etc.

Our 2019 conference programme is now finalised and we are delighted to have started receiving bookings. We are sure you will find the content both relevant and inspiring again this year – we have used last year's feedback to further improve what we can offer you – so book now to ensure you can take advantage of the Early Bird rate.



As usual don't forget to keep an eye on our website and use our forum for networking, sharing ideas and posting questions.

Becca and Heather
NAHH Co-Chairs and Trustees

Farewell and Welcome

We would like to thank our former Vice-Chair and say hello to our new Vice-chair and new Trustee.....

Thank you Lesley Spencer from all of us at NAHH for your commitment, enthusiasm and hard work whilst sitting on the Trustee Board, both as a Trustee and as Vice-Chair for NAHH.

Lesley's drive for developing palliative care services to meet the needs of those being cared for in the community setting has encouraged us all – as well as introducing us to many of her contacts in the palliative care world.

We would also like to extend a very warm welcome to Sally Taylor who has been on our Trustee board for a year and has bravely taken on the new role of Vice-Chair. Sally has an excellent track record of working in the community, caring for patients at the end of life in the Forest of Dean.

We are also delighted to announce that we have appointed a new Trustee – Helen Parkinson. Helen is a Clinical Services Manager at Wirral Hospice St Johns and has a background in the forces as well as a wealth of experience in working with vulnerable groups.

Welcome Helen – we are very pleased to have you on board!

Helen Parkinson – NAHH Trustee



I'm not sure how it all happened as I started my career as a volunteer in a mental health unit in the late eighties for free food and bus fares, but many years later I am proud to be a veteran. I have developed and progressed through a number of life changing and challenging times; from being on active duty, to my current post as the Clinical Service Manager for H@H, OPD, Intervention Pain clinic, Transition Lead for young people to adult services, and the Wellbeing Centre at St Johns Wirral.

As you can imagine, having served in the Forces certainly helps in my current role with project planning and juggling priorities. Since leaving the Forces and entering the hospice world via an unusual route, I have spent much of my career working with a challenging cohort of patients, mainly substance misuse and individuals working within the sex industry.

Working with patients who have limiting conditions and life style choices which make it hard to engage in traditional services, means that I have a strong passion for supporting those with learning disabilities and palliative care, as well as LGBTQB.

In my spare time I am a keen bee keeper, new mum to Lottie a labradoodle, and combine the two with Plot 3, my allotment.

I am looking forward to being part of the NAHH Trustees team, bringing a blended mix of knowledge, skills and challenges.

NAHH HCA Workshops

Health Care Assistant Workshops 2019 – still time to book!

In response to high demand last year, we are offering interactive study days for HCAs over the coming weeks:

- 18 June – Princess Alice Hospice, Esher
- 2 July – Douglas Macmillan Hospice, Stoke on Trent

Sharing Best Practice: Caring for People at Home who are approaching the End of their Lives.

The cost of places on these workshops is highly competitive so make sure you don't miss out

For registrations and for more information, please [click here](#)

Article of the Month

Two thirds of nurses struggle to provide good care to dying patients due to staff shortages

There is up to date research article on how nurses struggle to give good care to dying patients due to staff shortages and find not only the physical constraints but the emotional responsibility to care for the patient and the family is extremely challenging.

We all like to think we can give the precious gift of time but in reality there many barriers that prevent us from doing so and staff shortages is one of them.

[Click here](#) to read the article

NAHH Annual Conference 2019

Back to the Future: Respecting the Fundamentals
19-20 September
Kents Hill Park, Milton Keynes

We are delighted with the number of registrations we have received so far. Our exciting conference programme will follow the theme of retaining the essential services and qualities to be able to deliver high quality palliative care, whilst managing the challenges of economic and financial resource.

Check out the [programme](#) now!

As a member, don't forget you can take advantage of a conference discount through the [Early Bird Rate](#) available until 19 July 2019.

[Register Here](#)

Speakers

The conference programme has now been finalised and we are excited to include presentations from a great selection of [speakers](#)

Topics covered in the [programme](#) include:

- Workforce Resilience in Challenging Times
- Supporting Young People Pre and Post Bereavement
- Running a Night Service
- Wellbeing and Enablement

[and much more....](#)

Our keynote, conference chair and other invited speakers are all looking forward to interacting and engaging with you.

View their [biographies](#)

Call for Posters

We want to hear from you!

We are giving you the opportunity to display posters. We are particularly keen to have posters presented which can evidence the conference theme noted above. Posters are an ideal pictorial way to share your developments, innovations and ideas with others.

Posters could include successful innovations, new ways of working or preserving the core of what we do, for example.

[Submit an abstract](#)

Exhibitors and Sponsors

We are delighted that Roma Fundraising will be our Headline Sponsor again this year and would like to thank them and our other exhibitors who have signed up so far.

[View all our exhibitors/sponsors](#)

Keynote Speaker



Professor Philip Larkin

Professor of Palliative Care Nursing and Academic Director, University of Lausanne, Switzerland

Moving House: Workforce Resilience in Challenging Times

Conference Chair



Marie Cooper

Independent Nursing Consultant - Palliative and End of Life Care



What did you do to raise awareness during Dying Matters week (13 – 19 May)?

We quizzed our trustees to find out what their organisations got up to....

Princess Alice Hospice – “We held a variety of events including local quizzes, Death cafes, funeral myth busting talks, Schwartz rounds in local hospitals and provided shops and communities with coasters and bookmarks highlighting thought provoking information. We also displayed a vintage suitcase whereby people could submit their answer to the question of the day such as ‘Who is important to you’, ‘What would you like your legacy to be?’ etc. The suitcase contained items that represented important things in people’s lives – sparking people to consider what is important to them. Old family photos, jewellery, pets, the family home etc. There was a notice next to the suitcase saying “The average person spends 90 minutes packing a suitcase, did you know that you can write your Will in as little as 30 minutes?” (Becca Trower – Co-Chair)

St Peter’s Hospice – “I attended an excellent theatre production by Haylo Theatre. It was about 2 sisters coming to terms with the death of their parents. It was very poignant, perceptive and well researched. It covered the reality of coping with death through telling stories, relationships and the creation of memories. The power of the play was its ability to turn every day experience of death into a narrative that people have experienced themselves and can relate to. St Peter’s Hospice held an open evening in their high street café for local people to drop in and discuss issues related to end of life.” (Sue Eskins – Trustee)

Prospect Hospice - joined with the palliative care team from the local hospital and the community EOL team. “We attended 4 venues, hosted a talk, featured in the local newspaper and on 2 radio stations!! We engaged with 290 people. It was lovely to talk to healthy people about dying we had some very interesting conversations! Hopefully some of them will start thinking about getting some plans in place. Bring on next year!!!” (Jane Green – NAHH Trustee and Board Secretary)

Sue Ryder - took part in a county wide roadshow to promote Dying Matters week. Heather Mitchell, your Co-Chair was in the middle of Gloucester on the Health Promotion Bus speaking to the general public....

Great Oaks Hospice – staff from Great Oaks were also on the bus! “Tuesday 14th May, staff and volunteers from Great Oaks Hospice, we spent time on the Information Bus for Dying Matters week, which was based in Coleford Market Place, a little Market Town in the Forest of Dean. It was a bright sunny day and people were keen to come and find out more about what we were doing. In fact we made contact with 163 members of the public of all ages and discussed all aspects of being prepared. However one gentleman thought we were estate agents when we were talking about putting your house in order!!! This was also a great opportunity for us to gather feedback from the general public about their thoughts and opinions, fears and concerns about being prepared for the inevitable. We reassured people that just because they were talking to us didn’t mean they were nearing the end, merely that making plans for the future bought with it reassurance and peace of mind. We gave out information, signposted people to different organisations and had a beautiful fruit tree for the public to write a message on a paper leaf in memory of someone or to express an emotion which worked really well. It really was an enjoyable day.” (Sally Taylor – NAHH Vice-Chair)

It’s fantastic to hear about the creativity that organisations have used to engage with their local communities. It would be great to hear more from our members...

A Royal Visit

As Camilla, Duchess of Cornwall is the patron of Prospect Hospice, Prospect Hospice were lucky enough to have a ticket donated for a staff member to attend the Royal Garden Party. Jane Green, NAHH trustee and secretary was lucky and honoured to be voted in by colleagues to attend.

“I was very honoured to be chosen and even though the day was chilly with some rain, it did not dampen the enthusiasm of the participants. The royal gardens are truly beautiful and it was great to be able to visit some of the rooms on the ground floor of the palace. It was an added surprise to see not only her majesty but also Prince Harry and Princess’ Eugenie and Beatrice. It was a fantastic experience never to be forgotten.”

Jane Green – NAHH Secretary and Trustee



Day in the Life

When a HCA meets a funeral director- looking at the continued journey of care.....

Today I spent the day at funeral directors to see the continuing journey of our patients. Firstly, I want to thank them for such an opportunity and am privileged to share this.

They talked me through the journey of them first collecting a client, from the very beginning the care and dignity they give is second to none. Their passion and their vocation is shown in every step they take, because as they say you only get one chance at this, as is the same with our side of our patients journey. They document everything when they first collect someone they have boards where names are written where clients are collected from and where there service is, and the date in all the 3 branches.

They showed me the selection of coffins that could be chosen from traditional to wicker. There is a selection of different coloured silks to line, there's always a vinyl lining first for health and safety reasons and obviously you don't want anything to spoil the service on the day either. If you'd like a specific colour that's a bit different, they would do their utmost to get it as they want everything to be just right. They ask what clothes you would like to put on. If there's anything special they'll put it on, for instance if there's a particular hobby, maybe cycling and you wanted them in their cycling kit you could do that. Anything is possible.

Once your loved one is dressed they go into their personal chapel and remain in there for the whole time until the day of their service. Having a personal chapel allows families to come and go as they please and they can stay as long or as short a time as they want to. They feel this is a special time to spend with loved ones if they wish to. I felt this was such a lovely thing to be able to do.

They make an appointment to be seen in their premises or they come out to the home to talk about the service families wish to have and discuss music and hymns. They'll also ask families to pick some pictures of the loved one for the order of service. They'll ask about who, families want to do the service and then they tend to organise that part.

The funeral directors will show samples of the order of service available and once everything is picked they meet you again to finalise and send it to the printers. This is also available on a USB stick, so that at the service this can be put on a screen and scrolled through for people to see, which is a lovely because some people may not have seen these pictures or memories, so I felt that was a nice touch to the day.

On the day, they ring you just to check your all ok and to let you know everything is ready and what time they'll be arriving at your home with the carriage with your loved one. They make sure everything is just right and are in the background all through the service in case anybody needs anything at all. They get in touch after to give your loved one back to you if it has not been a burial, it's just ongoing because it is their life's work and they are so proud of what they do.

They make sure all the flowers are nicely presented outside when you come out of the service and if you want to take them home you can or they can deliver them to the hospice where the flower ladies put them in vases so all the patients and sitting areas have lovely fresh flowers. And finally they take you to your venue if you're having one or take you home if not. And if you need absolutely anything they are there for you.

The directors and their team are remarkable, it's a privilege to have had the opportunity to understand the process better, it made me feel that anybody's' loved one including mine would be given the most beautiful and dignified funeral that you could ever wish for.



Written by Julie Shanley, Health Care Assistant - Trinity Hospice, Blackpool

As we are all aware, hospices are encountering increasing resource pressures both in terms of finance and staffing. Many of you will have seen recent television programmes and news items discussing the challenges we are now facing. We thought it might be useful to share some links to a variety of articles and news items to ensure that everyone can keep abreast of what is happening;

[Rising costs and precarious "Jenga-like" funding model undermining capacity of hospices to meet demand for care](#)

Press release from Hospice UK, May 07, 2019

[Exclusive: UK Hospices face funding crisis as one in three forced to cut end of life Services](#)

ITV News-7 May 2019

An ITV News investigation has found hospices in the U.K. are facing a funding crisis, with increasing demand and rising cost of end of life care not being ...

[19000 signatures in petition bid to save Strathcarron Hospice from axe](#)

Evening Times-9 hours ago

Colin Lauder, NHS Lanarkshire's director of planning, property and performance, said: "Funding for Strathcarron Hospice was confirmed earlier this year by ...

[Your hospice is fighting a financial black hole](#)

Scottish Daily Record-22 May 2019

Staff are being asked to take voluntary redundancy or reduce hours in a bid to thwart compulsory job cuts. ... Hospices across the UK are under financial pressure. ... to Scottish Government for additional funding support and have welcomed a ...

[Lewis-Manning Hospice's inpatient unit closed due to funding issues](#)

Bournemouth Echo-7 May 2019

THE chief executive of Poole's Lewis-Manning Hospice said the decision to close its inpatient unit recently "was not taken lightly". In a letter to the Daily Echo, ...

[Willow Burn Hospice explains need for redundancies](#)

The Northern Echo-26 Sep 2018

TEN members of staff, including fundraisers, have been made redundant from a charity for people with life-limiting illnesses. Bosses at Willow Burn Hospice ...

[Acorns Children's Hospice to axe staff - blaming Brexit and slump in charity shop sales](#)

Birmingham Live-13 Feb 2019

Acorns Children's Hospice is set to shed jobs in a bid to save money - blaming a fall in income and the uncertainty of Brexit. The children's hospice has released ...

[Staff axed at The Donna Louise children's hospice in cost-cutting cull](#)

Stoke-on-Trent Live-11 Dec 2018

One of Stoke-on-Trent's best-loved charities is making 'a number of redundancies' in a cost-cutting cull. Five staff are being axed at The Donna Louise ...

[Helen & Douglas House positive about future, accounts say](#)

Oxford Mail-17 Jan 2019

A HOSPICE is starting the year with 'renewed optimism' for its future despite slipping further into financial deficit. Helen & Douglas House has published its first ...

[Cash-strapped hospice launches new appeal to help care for babies](#)

The Northern Echo-9 May 2019

... annual target to help our hospice stay open." Mr Guidery said their current financial situation was a result of a reduction of donations and funding from families ...

[DJ Liz Calls for rethink on cut to hospice funding](#)

Shropshirestar-13 Apr 2019 It was revealed this week that Severn Hospice has closed two beds at its Telford in-patients centre after seeing its funding from Telford & Wrekin Clinical Commissioning Group ...

Author: Mark Andrews

[Hospices care for 200,000 people a year, but they're powered by voluntary effort](#)

The Guardian- 8 Oct 2018 Adult hospices would be in an even better position if NHS funding support was both more substantial and more consistent, Ellis says. Across the country, it varies from 8% to 90% of hospice Author: David Brindle

Twitter

To keep up to date with the latest news regarding the NAHH please remember to follow us on  Twitter [@UKNAHH](#)

Feedback

Please feel free to share this newsletter with your colleagues and any feedback is gratefully received on

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Dates for the Diary 2019

18 June	HCA Workshop	Princess Alice Hospice, Esher
2 July	HCA Workshop	Douglas Macmillan Hospice, Stoke on Trent
19-20 Sept	NAHH Annual Conference and AGM	Kents Hill Park, Milton Keynes