

Celebrating 40 years of Care



"He and I could not have been looked after any better. You are all very special people. I cannot praise highly enough every member of the team." (relative)

Annual Review 2018-2019

Total support for patients and families
Clinical - Emotional - Spiritual - Practical - Financial

Introduction by Sarah Brocklebank

(Chief Executive)

Thank you for taking the time to read about Phyllis Tuckwell Hospice Care.

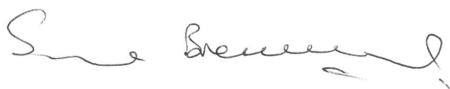
We are the only adult Hospice Care service supporting patients and families who are living with an advanced or terminal illness, across the whole of West Surrey and part of North East Hampshire - a catchment area of around 550,000 residents.

Our clinical, emotional, and practical support **helps our patients and their families to manage their symptoms and improve their quality of life**, helping them to make the most of the time they have left together.

We have always put our patients first - from the day we first opened our doors they have remained at the heart of all we do, and we are proud to be able to offer them such a wide range of specialist services in a variety of locations, including the Hospice in Farnham, Beacon Centre in Guildford, in care homes and in their own homes, so that they can choose the care that best suits them.

As an important local charity, we are committed to delivering high quality, safe, responsive, patient-centred clinical care, and are constantly improving our services to support our vision of providing **easy access to compassionate supportive and end of life care for patients and families in a place of their choice**.

As well as caring for our patients and their families, we also care for our staff and volunteers. We aim to treat each other with dignity, respect and understanding, ensuring that each individual feels valued and supported. We have established a culture of continuous learning and development, enabling our staff to reach their full potential – and because we invest in their education and training, our team is highly skilled and well-motivated. In fact, our education and training is so highly regarded that we have been acknowledged as a Centre of Excellence, and offer our specialist end of life care training to other local healthcare professionals.



Why do we do all of this? Well, at Phyllis Tuckwell we have a saying. This saying is at the heart of all that we believe and all that we do. We care for our patients, for their relatives and carers, and for our own staff and volunteers ... **'because every day is precious'**.



40 YEARS

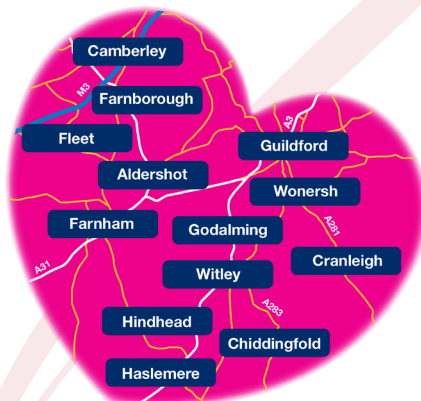
Phyllis[®] Tuckwell Hospice Care



2019 is our 40th anniversary, and since we first opened our doors in 1979, **we have cared for over 20,000 patients and their families!** We have grown and developed over that time, and the care we offer has grown too, as we have responded to the needs and preferences of our local community.

Instead of caring for patients solely at the Hospice building, we now work across West Surrey and part of North East Hampshire, ensuring that **our care is easy for patients and their families to access**, across the whole of our catchment area.

As well as the In-Patient Unit at our Hospice in Farnham, we also offer Living Well sessions at the Hospice and at our Beacon Centre in Guildford, and our Care at Home team visit patients and families who prefer to remain in their own homes. You can read about how each of these services helps our patients on the next few pages.



Matt's Story

"I was diagnosed with terminal cancer last year," says Matt, one of our Living Well patients. "Your world sort of implodes - it's all a bit of a blur really."

Matt was contacted by Annabelle, one of our Clinical Nurse Specialists, who visited him at home. "She went through a lot of detail about what was happening in my life," says Matt. "I was self-employed, but I gave up work. I couldn't go on. I had been working six days a week for 40 years, and then all of a sudden I'm doing nothing. It's a massive change to

cope with, as well as coping with the cancer. But Annabelle and Phyllis Tuckwell really helped. ***I was really interested when Annabelle told me about everything that I could do at Phyllis Tuckwell.***"

Annabelle told Matt all about our Living Well service, which is designed to help people who are living with an advanced or terminal illness, and who need support coping with everyday life. The team includes Doctors, Nurses, Therapists, Counsellors, Benefits & Entitlements Advisors, Dietitians and Chaplains, who together provide a range of care to promote physical, emotional and spiritual wellbeing. Together they help our patients manage the impact of their illness, cope with changes, improve their wellbeing and remain as independent as possible, and they also support the families of our patients too. Matt was keen to get involved, and started coming to one of our Physiotherapy sessions.

"The exercises were gentler than I expected them to be, but the next morning I could feel that I'd done them! They were things like holding onto the back of chairs and going up on tiptoes, and going from sitting to standing without using the arms of the chairs to help you. It was a gentle exercise but it was certainly what I needed. There was a group of about seven or eight of us and there was a bit of camaraderie going on, which was fun to join in with. I really enjoyed it."



Living Well

Matt has also had some complementary therapy treatments. *"The problem with the cancer I have is that it's in my pancreas,"* he explains, *"so lying down is really troublesome and having a massage can be problematic."*



*Vanessa, the Complementary Therapist, said we could try reflexology instead. **I've been to her three times now and she's been wonderful.** The last session I had, although she was doing the reflexology on my feet, by the time she'd finished the pain in my stomach had gone. She's so nice, we chat about our lives and it's lovely. I look forward to it. **You come out feeling so refreshed. It takes my mind off the cancer and I feel so invigorated afterwards.**"*

Matt and his partner have also had counselling, which they have both found beneficial. *"We've found it really helpful, because a cancer diagnosis is such a massive thing to go through. **Between the two of us we've been well looked after in that way.**"*

As well as physical and emotional support, we have also offered Matt practical help with filling out forms to ensure that he is claiming the correct benefits. *"I'd never had to draw any benefits in my life,"* he says. *"I didn't want to face up to it. Having worked all my life, for me it was another 'stop'. Filling in all those forms, I wanted someone else to do it. Annabelle said that Phyllis Tuckwell's Benefits & Entitlements Advisors could help with that. I didn't need them in the end, I managed to do it myself, but **knowing that they were there if I needed help was reassuring.**"*

Matt continues to see Annabelle, who keeps a close eye on his situation. *"She found out that I love art and told me about the Brush with Art class which they run at the Hospice on a Monday. I hope to start going along once I've finished my current course of chemotherapy."*

***"The help I get from Phyllis Tuckwell makes a massive difference.** When all about you is falling apart, there is that feeling of security that there's someone there. They were there when I was at my lowest, and have been ever since."*

"The word 'Hospice' scares a lot of people," says Matt. *"If I say to my friends that I'm going to the Hospice, they look at me with horror! They think I'll be there for a couple of weeks and that'll be the end of it. So I explain that I'm coming here for counselling or an exercise class or reflexology, and that 'Hospice' is just the name of the building. They're associating it with end of days rather than better days. Before I'd been here, I had that feeling too, but as soon as I walked in the building I didn't feel that way. **I feel comfortable coming here. It's a place of positivity.**"*

Beatrice and Sue's Story

Sue had been nursing her mum Beatrice for five years when things finally got too much for her.

"Mum had got progressively worse in quite a short space of time," says Sue. "She had breast cancer, dementia, osteoporosis and was double incontinent. She couldn't walk anywhere on her own. I was almost having to carry her to the bathroom to clean her, and to the bedroom. Once she had become bed-bound it was very difficult for me to care for her on my own. I couldn't nurse her in the way she needed to be nursed. I'd looked after her for five and a half years; I felt that I should have managed. But there comes a point when you just can't do it on your own anymore."



Beatrice was referred to Phyllis Tuckwell and cared for by our Hospice Care at Home nurses, who visit patients who have chosen to remain at home in their last weeks of life.



Care at Home

"Mum wanted to stay at home," says Sue, "and because of Phyllis Tuckwell she could. When the door went, we used to say 'our angels are here'. They loved coming to see her. There was a nurse called Pat and she always had cold hands. Mum would say to her 'You've got cold hands!', and Pat would call out to me 'Sue, I'm getting told off again!' There was always that joviality. When the door went in the morning, we used to say 'our angels are here', and I do feel strongly that's what they were. **I knew the care that they were going to give to my mum was going to be second to none.** They loved her, they cuddled her, they treated her like one of their own, and they did the same to me. They were never short of a hug. **They took all my concerns away."**



"Before they started coming I used to get a heavy feeling in my chest. But once they started visiting, I didn't have that feeling. They gave me back the quality of time with my mum that I needed. They took all the pressure away, so I could feed Mum, and sit and have a cup of tea with her. I always thought I could cope on my own, but I realised I couldn't do it without their help."

"On the morning that Mum died, the nurses came as usual. I remember hearing them laughing with her. Within two hours of them leaving, she had died. I phoned them and they came straight back. They sorted Mum out and stayed with me for quite a long time. There was no rushing; they made sure that I was ok before they left."

"When the doctor first came out to see us, I thought Mum only had a couple of weeks left, but she went on for another eight weeks. I put that down to the care those nurses gave her, that I got those extra weeks with her. They were also there for me. They know what you're going through. It's comforting, knowing that they remember me and still think of my mum."

Peter's Story

Our In-Patient Unit (IPU) is probably the best known of our services and is usually the one which most people think of when they hear the word 'hospice'. However, many of the patients we care for on the IPU are admitted for symptom management and return home once they feel better. Earlier this year we helped Peter, who came to stay on our IPU for two weeks while we managed his medication and brought his pain under control.

"I've had cancer for 19 years and I've been in excruciating pain for most of that time," says Peter. "The pain has worsened over the years and I got to the point where I was taking 32 pills a day! Some were for the cancer, some for pain control and some to counter the effects of the other pills. In the end my GP referred me to Phyllis Tuckwell, to see if they could help. I didn't really understand what they were going to do for me, I just knew it was for pain control."

Peter came to the Hospice to see Cate, one of our Doctors. *"She suggested I come in and stay on the In-Patient Unit, so that the Doctors there could analyse my medication and adjust it. **I came into the ward in excruciating pain and walked out two weeks later pain-free.** Over four days they looked at my drugs and substituted some with others, changing them and reducing the number I was taking. At the end of four days they were then able to calculate my new drug dosage. **My pain is now zero – it's under control. It's gone, it doesn't exist.** When they ask, 'what's your pain level?', it's nothing. But without the drugs, it would probably be about six million!"*



While Peter was on our IPU he received a surprise visit when a local alpaca owner bought two of his alpacas to the Hospice. Many patients find comfort in stroking and petting animals, and over the years we have had visits from many different animals including cats, dogs, birds, goats,

In-Patient Unit

donkeys and guinea pigs. The alpacas visited patients on our IPU before heading to Day Hospice, where they were petted by patients at our Living Well sessions.

“The Alpaca Therapy was without doubt a major contributing factor in the successful outcome of my treatment!” laughs Peter. ***“They were brilliant!”***

Peter stayed on our IPU for two weeks, after which he went home. The Doctors gave him some drugs to take with him, in case he experienced any breakthrough pain. ***“Cancer pain is there all the time,”*** he explains, ***“but occasionally it peaks and it’s worse than it has been, and that’s breakthrough pain. You need to stop that, or else it stays at that level. Since leaving the IPU, I’ve found that I’ve hardly ever had to use the drugs at all.”*** Other than the occasional breakthrough pain, which Peter was able to control using these additional drugs, he has been pain-free since leaving IPU.

As well as receiving care from our CNS and Doctors, our Occupational Therapists have also helped Peter. ***“They’ve been to my house and arranged for a second handrail to be fitted, and grab rails to be put in the bathroom. I’ve had two back operations, and during those times I couldn’t get into the bath, so they lent me some equipment to help me get in and out of the bath. Now I can do it on my own, because I’m so much better.”***

“Phyllis Tuckwell has changed my life,” says Peter. ***“I know I am not cured, but they’ve helped me to live a normal life. People say I look and act totally different from how I was before I went into the IPU. The pain was unbelievable, but I feel so much better now. Phyllis Tuckwell’s Doctors have been brilliant, absolutely brilliant. Everybody I have met at Phyllis Tuckwell has been superb. They’re professional, they have a sense of humour***

and they’re fun! Everything they do is right. They think outside the box – particularly the Doctors. The Doctors know about pain, and they know about how to stop pain. They understand how to control it. ***I went in to Phyllis Tuckwell crawling up the wall with pain, and I walked out pain-free for the first time in 15 years.”***



Improving our care

2018/19 has been another extremely busy and successful year for Phyllis Tuckwell, and good progress has been made as we conclude our 2016-2019 strategy.

We have
firmly embedded locality working into PTHC and have integrated our services alongside our external partners
to provide seamless care for patients and their families.

We now
routinely provide Living Well services
from both the Hospice and Beacon Centre.



We are
working in partnership with our two Acute Trusts,
Royal Surrey County Hospital (RSCH)
and Frimley Park Hospital (FPH).

Following extensive consultation both externally and internally,
our new referral criteria were introduced
in December 2018, designed to promote appropriate early referrals to our services.

We continue to promote this, together with our Advice & Referral Team (ART), to GPs and other healthcare professionals.

In June 2018 we unfortunately had to close temporarily four of our eighteen IPU beds due to a high level of nursing staff vacancies.
However, following a number of successful recruitment initiatives, we were able to reopen one of the closed beds
in September 2018 and we are actively working towards reopening another during 2019/20.



**EMIS (our clinical database)
was successfully
introduced**

in July 2018 -
both on time and on budget.
Since then we have been working
hard to ensure that we get
appropriate information sharing
agreements with GPs
to enable records to be
shared and maximise the full
advantages of this database.



In March 2019
**we appointed our second
Clinical Educator,**
giving us a strong base for
developing our education activities
both internally and externally.

**We have continued with
our research activities**

participating in five national
and local research studies
in conjunction with different UK
universities. We have also published
articles in UK journals and our
clinical team have presented eight
posters at different UK conferences.



**We have delivered
our 2018/19 income
generation targets**

and are pleased to report that
our Retail profit has
totalled 13% over that
which was budgeted,
our Corporate Fundraising
is 33% ahead of budget
and also of 2017/18's
corporate income, and
our Appeals income
is £24k above budget
despite the introduction of GDPR
and the impact this has had on
contacting supporters.

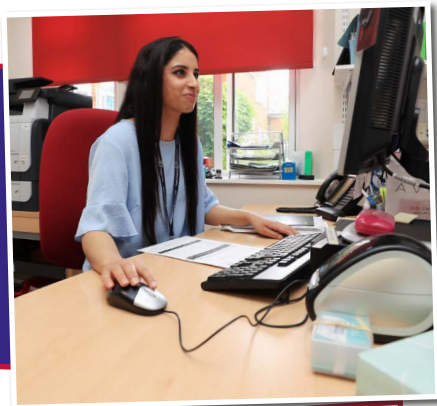
Following the introduction of GDPR,
**a Data Protection
Advisory Group oversaw
the different activities
required to successfully
comply with the
introduction of GDPR**

in May 2018. This group continues to
monitor all information governance
activities within PTHC.



Our care in numbers

We received
1,498 referrals
to our services,
a 13% increase on 2017/18.



We supported
2,175 patients,
a 10% increase on last year.

This is the first year that we have supported
more than 2,000 patients in a year -
hugely encouraging, as our strategy is to increase
the number of people who benefit from our services.



We supported
988 carers,
15% more than last year,
enabling them to provide compassionate care
for their loved ones. We care for the whole
family, not just the patient.

Living
Well

Our
team supported around
600 patients.

Referrals
to our
Care at Home
service have
increased
by 14%, to 1,394,
supporting patient choice
to be cared for at home.

The
In-Patient Unit
supported
317 patients.

We would support more if we
could recruit more nurses.

99%

of those who completed our
VOICES survey said that they would
recommend PTHC to friends or family
if they were in need of similar support.

Our VOICES survey
showed that
the care received
from both doctors
and nurses
on our IPU was rated very
highly, with 99% in the
exceptional or
excellent
category.

**A total of 567
local healthcare
professionals**

attended one of our education
sessions in 2018/19,
an increase of 9% from last year.

Donations are our life blood

Our work is only possible thanks to the generosity of our local community, through donations and volunteering, as we spent £11m in 2018/19, with only £2.3m funded by the NHS/Government.

£2.3m raised through our 19 shops.

£1.9m raised through legacies – 1 in 5 of people we helped last year is thanks to someone who has left us a gift in their Will.

£216,000 raised through community events, including fetes, balls, garden parties, concerts...

£288,000 raised through local businesses, their employees and customers.

£437,000 raised from Trusts.

£831,000 raised by our lottery - Tuckwell Chase Lottery.

£1.4m raised through donations, appeals, and other activity.

70p in every £1 we spend goes towards patient care.

For every £1 we spend on fundraising, **we raise £3.**



£10.8M
total income.

Our local community is amazing!

With our community's help we raised a total of £10.8m in the 2018/19 Financial Year - and here are just some of the ways we did it...

£217,000

was raised by people taking part in sponsored events organised and supported by PTHC. These included 18 people completing the London Marathon and around 3,000 people in our other events including Bubble Rush, Dash of Colour and Walk for the Wards.



Again last year many local community groups and organisations chose to adopt PTHC as their chosen charity.

Over £130,000

was raised by local Rotaries, Lions, Golf Clubs, Churches and our very own support groups.

An incredible

£30,000

was raised from collection tins

in shops, petrol stations, bars, dentists, doctors, shopping centres etc.



6,686 children from 37 schools

ran like Rudolph in our annual Reindeer Runs, raising just

over £60,000.

Thousands of miles

were covered by our supporters as they climbed, cycled, abseiled, swam, walked, ran and even zip-wired across the UK and overseas. Many others took on just as demanding personal challenges, giving up alcohol, going vegan, shaving their heads or even waxing their bodies. Together they raised

an amazing £150,000.

66 Trusts and other grant-making institutions supported Phyllis Tuckwell last year.

Their donations are crucial to our work and we thank them for their generous donations, which have enabled us to purchase specific pieces of equipment or support service developments.

So many of our events are only made possible with the help of our 1,000 volunteers who together offer a total of around 140,000 hours a year to support our cause – that's equivalent to 16 volunteers helping us every hour!

Our Trustees, Officers and Contacts

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your support!**