

Our patients tell our story better than us



**Phyllis[®]
Tuckwell**
Hospice Care
...because every
day is precious



*"We both found the support and care of all the staff we were in contact with amazing. We could not have coped without them."
(Relative of patient)*

Annual Review 2019-2020

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

Introduction by Sarah Church

(Chief Executive)

Welcome to our Annual Review, which marks the beginning of our new five-year strategy (2019-24).

We are extremely proud of what we achieved over the past 3 years, so our new strategy builds on that success and aims to reach more people than ever who need our care.



We know that the Covid-19 pandemic will have a significant impact on PTHC, so we are doing all we can to mitigate the challenges and focus on finding new ways to help patients and their families. 19/20 was an extremely busy and successful year. We have seen the benefits of our single Advice and Referral Team (ART), which provides a seamless link into our three clinical service areas: In-Patient Unit (IPU), Care at Home and Living Well. This, alongside our new clinical IT system, which links in with all our local GPs and two acute hospitals, has made it easier not only for our referrers and Clinical team, but for all our staff and volunteers, to provide timely and appropriate care for our patients and their families. We have focused on delivering these remodelled services to more patients and families than ever, providing the best possible quality of care to those who are living with an advanced or terminal illness, in our catchment area of West Surrey and North-East Hampshire. Increasing our education, learning and development activities have also been a key focus for us, strengthening our working relationships with other healthcare providers and improving the overall end of life care provided in our local area.

The Covid-19 pandemic hit the UK in March 2020, at the tail end of our 19/20 financial year. Although not impacting on our results for 19/20 greatly, its effect for the next 12 months and beyond will be significant, in terms of both service delivery and finances. At the time of writing, forecasting for this is impossible to predict, but we are confident that our reserves and the actions we have taken to maintain levels of fundraising, combined with increased Government funding, will hold us in good stead into 2020/21, and enable us to continue to deliver our care in the local community.

The strong underpinning strategy and robust financial health of our organisation are thanks to the hard work and leadership of Sarah Brocklebank, who retired as Chief Executive at the end of March this year, and the Senior Management Team here at Phyllis Tuckwell. I joined in March and would like to thank Sarah for her dedication to Phyllis Tuckwell. I am confident that we are in a good position to come through the pandemic strongly.

I hope you will find this Annual Review helpful and informative. Thank you for taking the time to read about our work.

Sarah Church

2019/20 Report

This document contains a report of the year's activities, but the Coronavirus pandemic has impacted our services hugely, affecting every area of our care, and many things have changed because of it. We are the only adult Hospice Care service which supports patients and families living with an advanced or terminal illness, across the whole of West Surrey and part of North East Hampshire. By working quickly to adapt our services, we have been able to ensure that we can still support our patients throughout the pandemic, and be there for their families too.



As our Living Well group sessions were suspended due to the pandemic, we started delivering our care through telephone and video calls, which enabled us to assess patients' needs and provide much-appreciated social contact for those who were feeling isolated because of the lockdown measures. Care at Home staff started wearing full PPE for every patient visit, and we extended our working hours, increased our weekend medical and nursing care, and launched a night visiting service for those who had chosen to spend their last days at home.

We redeployed staff from other teams so that we could open all of the beds on our IPU, and created isolation rooms for Covid-positive patients. All IPU staff were provided with appropriate PPE, and visiting restrictions were put in place to help reduce the risk of infection.

It is important for patients and families to stay connected, and our Pastoral Care team introduced a range of innovative ways to help with this, including comfort pebbles, holding crosses and vigil candles. They visited IPU patients daily, sitting and talking with them, and reading out messages from loved ones who were unable to visit.

Our IT team worked hard to ensure that our non-clinical staff were able to work from home, and our Fundraising team launched a range of virtual fundraising events to help minimise the impact that our shop closures and cancelled fundraising events would have on our income.



We will continue to adapt as the Coronavirus situation changes, meeting the challenges it presents to ensure that we can continue to be there for our patients and their families, and for each other **...because every day is precious.**



Andrew's Story

15 years ago, when he was 18, Andrew was diagnosed with a brain tumour. He had several operations, but was eventually given the news that there was nothing more that could be done for him. Doctors estimated he had three months to live.

"That was six years ago," he says. "I was told to get in touch with my local hospice and start to arrange things with them. My family and I were horrified. The word 'hospice' filled me with fear; I thought it was somewhere that you go for your final weeks - but it was completely different to my expectations."

*"We got in touch with Phyllis Tuckwell and they arranged for me, my wife Caroline, and our daughter Bethany, to start having weekly counselling sessions, to help us get over the initial shock of my prognosis. The counsellors would come out to our house or to my place of work, and would fit in with when we were free. It really helped. Bethany was only three then, and it was very difficult to tell her that her daddy hasn't got much longer to live, but **the counsellors knew exactly how to deal with somebody of her age.**"*

At the time, I was disabled but I could still do things for myself. However, as we didn't know what would happen in the future, Phyllis Tuckwell's Occupational Therapy team came to our house and put in a lot of equipment to help me. They had rails installed outside, and inside provided me with bath equipment to help me bathe, and equipment to help me get on and off the bed independently."

"After seeing the Occupational Therapist, I was introduced to the Physiotherapy team. At that time I was using a wheelchair, and I missed the independence of being able to walk around on my own. They helped me to get walking again, using walking aids, and they've helped me with my balance and stamina too."

Andrew was also invited to our Day Hospice sessions, which are held at the Hospice and Beacon Centre. Day Hospice is part of our Living Well service, and at these sessions patients can access nursing care and complementary therapy treatments, attend physiotherapy and occupational therapy groups, and meet others who are in a similar situation to them.

*"I started coming once a week for 12 weeks," says Andrew. "There was a group of ten of us, and it was fantastic! **The staff and volunteers were so friendly, so supportive, and nothing was too much for them. They made me feel very relaxed and welcome.**"*



Living Well

Our Living Well service is tailored to patients who need help managing everyday life. It offers a range of individual and group support, including: movement therapies, which are designed to help with symptoms such as fatigue and poor mobility; relaxation therapies, aimed at helping those who are experiencing breathlessness, stress, anxiety or low energy levels, or are having trouble sleeping; emotional therapies which help participants to express their feelings and teach strategies to help them cope with the emotional impact of their illness; and creative therapies, which enable participants to explore their creative side and find an outlet for their feelings. There is also support for patients' families and carers, enabling them to find time and space for themselves and learn practical ways of coping.

"There are different sessions on offer every week and you can go along to them if you want to. You're not pushed into going, but they really do help you when you do go," says Andrew. "I've gone to the 'Learn to Relax' session, which is led by the Occupational Therapists. You sit in a comfortable chair, listen to nice music, and they help you to imagine that you're on a beach or in a nice garden with nobody else around. You can just close your eyes and imagine you're there, and relax. It also means that you can bring that experience with you and use it when you're at home, when you can't sleep or when something's bothering you."

"There are also the mindfulness sessions, which help you find different ways to think about stresses and bad thoughts. You learn a different way to see things; a different way to breathe. There's a lot on your mind when you've got cancer, and I found those sessions very helpful. Caroline, Bethany and I have also attended the 'Therapies Through Nature' group, where we created a vegetable trug together."

*"The support from the other people who attend the Living Well service is fantastic. I'm quite shy really, so to come along was against what I would normally want to do, but it made a real difference to me. **It's nice to talk to people, and meet staff and volunteers who are there to help you.** We all have a great laugh. You can forget about the worries you have and stop thinking about things that are going to happen in the future. The staff and volunteers are always there to support you and help you, and not just for the 12 weeks that you attend Day Hospice. They're always there for you and they will always remember you. I know that I will be able to come back to the Living Well service if I need to."*



"The Living Well activities have made a massive difference to my life - not just mine but my family's as well."



Jack's Story

“When I was referred to Phyllis Tuckwell, I was introduced to Annabelle,” says Jack. “She’s been coming to see me here for about two months now, and she’s been a diamond.”

Annabelle is one of our Clinical Nurse Specialists (CNSs). Our CNSs are often the first members of our team to see a new patient and are pivotal in assessing each individuals’ needs and the needs of their families. They can refer patients on to other services within PTHC, such as physiotherapy, occupational therapy or complementary therapies, and can also offer complementary therapies, counselling, and practical support to patients’ families and carers. Annabelle referred Jack for some complementary therapy sessions, and he was visited by Jenny, one of our Complementary Therapists who works in the community, visiting patients and families at home. Jack has had hand massages and Reiki, which are just two of the many therapies which we offer to help ease symptoms such as pain, anxiety and fatigue, and promote wellbeing.

“I’ve never had so much fuss made over me!” says Jack. “They’re all lovely. It’s nice that they come here. I can’t walk far because of my knees. 200 yards and that’s my lot. I’m frightened of going too far away from home.”

“Phyllis Tuckwell has been a lifeline for the whole family,” agrees Jack’s granddaughter Yasmin. “It’s that support that you don’t get in the real world! Having somebody to come and help Grandad at home, it’s like gold really. Because he

Care at Home



lives on his own, I try to visit as often as I can, but now he'll say to me 'Jenny's coming round for my Reiki today so I don't need you to come for a cuppa, I'm busy!' It's something that he looks forward to; it breaks up the week. And it's support for us family members too, because I worry about Grandad.

Just knowing that other people are coming round to help, it takes a little bit of that strain off."

As well as caring for Jack, Phyllis Tuckwell have also supported Yasmin too. "I've just started counselling and it's amazing" she says.

"You go there and for that time you're safe, you don't have to worry about anything. Everything's so fast and aggressive now in life, but with Phyllis Tuckwell everything slows down a little bit and you've got that kindness and caring around you. The fact that everybody's supporting you, it's priceless."



Paul and Carol's Story

"Paul was always a very active, sporty person," says Carol.

"He played golf and bowls every week, and we both loved going cycling and playing tennis with friends. We would organise skiing trips and walking holidays every year, and were also volunteer Puppy Walkers for the Guide Dogs Association. After our last puppy left for training school

in 2018, we decided that we'd have a short break and then take on another pup for a year, but that all came to a halt when Paul became ill."



Paul was diagnosed with skin cancer in July 2019. As his illness progressed he was referred to Phyllis Tuckwell, and in November he and Carol were visited by Pam, one of our Clinical Nurse Specialists (CNSs).

"Pam would visit us at home," says Carol. "She would ask Paul how he was feeling and adjust his medication if it needed changing at all."

Paul's condition deteriorated throughout February, and he spent a week in the Royal Surrey County Hospital.

"When he came home, we were visited by Phyllis Tuckwell's Occupational Therapy and Physiotherapy teams, to loan us some specialist equipment for him to use. We also had a visit from Dr Sarah, who reviewed Paul's condition, as it had worsened quite significantly. She referred Paul to the Hospice Care at Home service, and we had a visit from Aileen, one of the team, soon afterwards, to find out what help we needed. Two of their Health Care Assistants also started visiting us twice a week to help Paul with washing, shaving and changing clothes."

*"Following Dr Sarah's visit, Pam was available to further discuss pain management and medication. **Having those visits from her, and the weekly phone calls she made to us too, was really reassuring.** I was also able to call Phyllis Tuckwell's Medical team if I was unsure of how to handle any medical issues that arose or needed to clarify*



In-Patient Unit

drug usage. **The ability to call and speak to someone at any time was a great lifeline for me.**

As Paul's illness progressed, Pam suggested that he be admitted to the In-Patient Unit (IPU), where he could receive 24 hour specialist medical and nursing care. *"His symptoms had become more acute,"* says Carol, *"and he needed the medical and nursing care that the IPU would provide. Pam was very timely in her recognition of this."*

"Both Paul and I felt the inevitability of the journey we were on. Paul accepted the need for us to take this next step of going to the Hospice; he knew it would help relieve the pressure on me, and that he would receive the increased medical care he now needed. His condition had worsened quickly, and it was really hard to watch the physical and mental changes that he was experiencing as it became harder and harder for him to do things that he was previously able to do."

*"Paul was admitted to the IPU on Easter Sunday. **We were met by a very helpful and caring professional team, in a calm environment.** His room was quiet, bright and comfortable. Because of the Coronavirus restrictions, visiting had been reduced to 6pm-7pm each evening, which meant that Steph, Paul's daughter, and I had to visit on alternate days. We were just glad that we were still able to visit though."*

*"As well as this being the next step for Paul, it was also a big change for me - the beginning of the end after so many months of caring for him at home. It was hard to suddenly change from being a carer for so long and then to relinquish that care. As his symptoms worsened, Paul needed much more help with mobility, eating and personal care, but the nursing staff helped him with all of these things. **They were attentive and considerate; they talked to him and listened to his responses. It was a great comfort to see that they didn't just focus on his illness, but cared for him as an individual.**"*

*"Paul's final days were long and drawn out, and really quite harrowing. The staff at Phyllis Tuckwell supported all three of us throughout, though. Chaplain Jill visited Paul daily and got to know him well. She was a huge comfort to us all at the end of his life. **She and all the staff treated both me and Steph with exceptional kindness, respect and consideration at every visit.**"*

"Phyllis Tuckwell has a strong support system in place following a patient's death and they phoned me to ask how I was doing, and to remind me that they are there to help if Steph or I need them. It's comforting to know that they're still there for us."

Improving our care

Introduced a new database, EMIS, in July 2018, allowing information sharing which has improved patient care and increased efficiency.

Participated in the NHS medical training programme, earning a good reputation for training and supporting Doctors and other Clinicians.

Piloted and implemented the National Early Warning Score (NEWS) on the IPU, to identify clinical deterioration and the need for escalation.



Held our Annual Family Day for bereaved Families at Mytchett Lake.

Reviewed our volunteer Hospice Home Support service, renaming it as Home Support.



Introduced 'Quality Matters' and 'Research Works' newsletters to staff, to highlight key information, feedback and learning.

Started to implement a rolling programme to ensure our services are available to hard-to-reach communities.

Held a workshop on 'Supporting Patients with Learning Disabilities and Autism and the LeDeR (Learning Disability Mortality Review) Programme'.

Identified a Consultant to be PTHC LeDeR lead.

Adapted all clinical services to respond to the Covid-19 pandemic, to ensure the safety of patients, visitors, staff and volunteers, whilst supporting NHS services, including extending the Advice & Referral Team's working hours.



Launched our new website with clearer navigation, improved information, and online booking facilities.



Introduced new Nurse recruitment initiatives and developed nursing career pathways.



Living Well and Patient & Family Support services have continued to support patients and families by telephone and video calls throughout the pandemic.

Considered our environmental footprint in fundraising activities, e.g. providing water refill stations instead of bottled water at our events.

Recruited our first Legacy Officer to focus specifically on Legacy fundraising.



Our care in numbers

Overall referrals increased
by **4.4%** over the last year.

We support around

3,000 people

every year.

48% increase
in referrals to
Living Well service.

3% increase
in number of
carers supported.

The number
of patients going
home from
the IPU

after symptom control
and pain relief

has increased

from **18%** to **27%**

For the first nine months of 2019/20,
15 of our 18 IPU beds were open.

A **16th** opened in January 2020,

by March all **18** were open

as we redeployed staff from our community teams
to assist the NHS with the Covid-19 pandemic.

Around **20%** increase
in number of patients cared for by our
Care at Home team.

Participated in

five

national and local research
studies with UK universities, completed surveys in
further studies and one oral presentation,
published articles in

five

UK journals.

Presented

three

posters

at UK conferences.

Five

81%

increase in
attendances
at PTHC Education
training sessions

and training continues online, until
social distancing restrictions are lifted.

Nine

staff members
joined Apprenticeship
programmes.

Our VOICES survey of our patients
and families showed that:

In our annual VOICES survey
with bereaved families, they
stated that

91%

of our Care
at Home patients
achieved their
preferred place
of death

(where preferred place
of death was known).

98%

of respondents would
recommend PTHC to
friends and family if
they were in need of
similar support.

All

IPU respondents
agreed that there
had been enough nursing
care and help available.

92% rated the care received from doctors
and nurses as exceptional, and 96% rated
it as excellent. When asked if the patient
was treated with dignity and respect,
93% said 'always'.

96%

of Care at
Home respondents
said the care
received was
exceptional,
excellent or good.

83% felt that the patient always
saw a nurse as often as needed,
and 89% said they and their
family had received enough
help and support.

90%

of Living Well
respondents said their
loved ones had definitely
benefited from
attending sessions,
and they themselves had felt supported
by the Living Well Team.

Donations are our life blood

It cost £11.8m to provide our services this year. Around 20% of our income comes from Government/NHS, and the rest raised through fundraising activities. These include donations and gifts in wills, events, community fundraising, charity shops, local businesses and grants from Trusts.

In March 2020, we cancelled many of our fundraising events and closed our shops in response to Covid-19 which, although only having a minor effect on this year's results, will have a significant impact on our income in 20/21.

£1.5m raised through our 19 shops.

£1.4m raised through legacies – the care of 1 in 5 of our patients is funded by gifts in Wills.

£794,000 raised through community events, such as fetes, cake sales, concerts...

£270,000 raised through local businesses, their employees and customers.

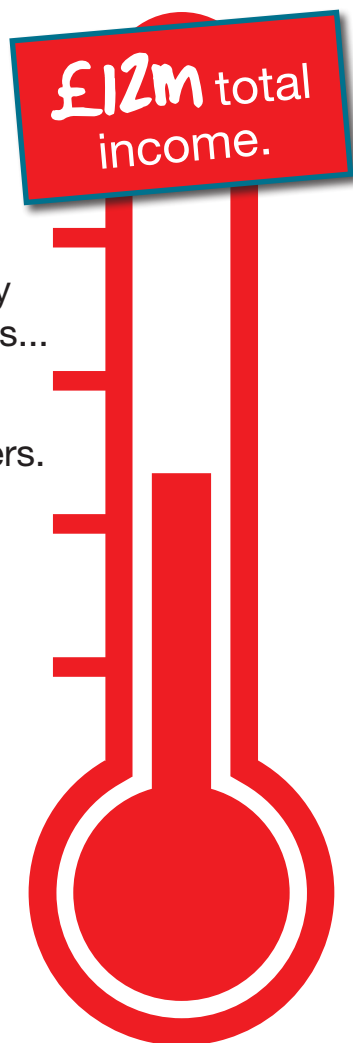
£367,000 raised from Trusts.

£918,000 raised by our lottery - Tuckwell Chase Lottery.

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

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

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



Our 40th anniversary

We celebrated our 40th anniversary with some memorable events:

Celebration service at St Andrew's Church.



Thank you
open garden event
for our volunteers.

40th anniversary video,
seen by nearly 10,000 supporters.

Staff celebration party



Mobile exhibition
with highlights of PTHC's 40 years,
displayed throughout our
catchment area.

Launch of red, white and rose
PTHC Anniversary wines.

Music in
the Park

Soapbox
race



Just Kampers
weekend

Our Trustees, Officers and Senior Management Team

President

Chris Tuckwell

Chief Executive

Sarah Brocklebank (retired March 2020)

Sarah Church (from 1st April 2020)

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Board of Trustees

Michael Maher (Chairman)

Dr David Eyre-Brook (Vice Chairman)

Ian Trotter (Vice Chairman)

Rosy Anand

Professor Michael Bailey

Veronica Carter

Helen Franklin

Ken Ratcliff

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Alison Huggett

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Robert Laing (from February 2020)

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