

"There's always somebody here who can help, and nothing is too much of a problem. It's been a brilliant experience."

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

## A successful year

Sarah Brocklebank Chief Executive

July 2017



## Welcome

Welcome to our latest Annual Review, which I hope you will find interesting and informative. It details all of the important information about our services, achievements, income and expenditure over the last financial year.

2016/17 has been another busy and exciting year for us, and an excellent start to our 2016-2019 strategy. The acquisition of the Beacon Centre in Guildford has enabled us to work across two sites and create one seamless service for patients and families, at the same time as laying strong foundations both internally and with our external healthcare partners, which will help as we introduce locality working in 2017/18 (see page 14). Recent CQC inspections of both the Hospice and the Beacon Centre sites resulted in us being awarded 'good' and 'outstanding' ratings.

Strong medical and nursing leadership, along with a review of working practices, has enabled us to increase our In-Patient Unit (IPU) admissions by 12% from 2015/16, to our highest level yet. We have also continued to grow our Community team, which now cares for around 1,700 patients a year, enabling them to spend their last days in their own homes.

By strengthening our Education and Training team, we have developed a clear strategy for the internal and external courses which we offer, ensuring we share best-practice in End of Life care with other healthcare professionals. We are also increasing our research activities and participate in clinical trials and research programmes on a local and national basis.

Funding our work is our Income Generation team, which not only hit income targets in 2016/17 but achieved a higher profitability and return-on-investment than budgeted in virtually every area. A series of focus groups and structured interviews which we ran last year have enabled us to ascertain the appropriate language to use in our communications, which we have incorporated

into our literature. It was so successful that we were asked to share our findings at the national Hospice UK conference.

Reflecting our drive to provide our staff and volunteers with a supportive, positive environment, we carried out a survey to assess what we do well and what we could improve, and were pleased to learn that we outperformed other hospices and charities in almost all areas. Action plans have been developed and implemented to improve staff and volunteer satisfaction even further.

We have included stories from two of our patients within this Review, to illustrate the positive impact which our services have had on their lives.

For more information about our work, please refer to our Annual Report, Three-Year Strategy Report or get in touch.

## Thank you for your support!

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Phyllis Tuckwell Hospice Care (PTHC) is the only adult Hospice Care service supporting patients and families who are living with a terminal illness, across the whole of West Surrey and part of North East Hampshire. We offer our care at the Hospice, at the Beacon Centre and at home, across a catchment area of around 550,000 residents. Our care helps patients manage their pain and improves quality of life for both them and their families.

Seeking Hospice Care isn't about giving up hope or hastening death, but rather a way to get the most appropriate care in the last phase of life...

#### ...because every day is precious.

We are one of the larger Hospice Care services in the South East, with 18 beds on our In-Patient Unit and a growing Community team. Last year we cared for around 2,000 patients and their families living with a terminal illness, helping them to make the most of the time they have left together.



Our mission is to care compassionately for adults living with a terminal illness, and those closest to them, so that they have the best possible quality of life and the patients' final days are peaceful



We offer In-Patient services, through our 18-bed In-Patient Unit (IPU), and Community Services through our Clinical Nurse Specialists, Day Services, outpatient appointments and our expanding Hospice Care at Home team, which means patients and carers have a choice about where and how they want to receive care and treatment.

All our services are provided to ensure the majority of our terminally ill patients spend their remaining days at the place of their choice.

Our services extend beyond the patient, to their relatives, carers and friends through our pre- and post-bereavement services.

### **Community Services**

Our Community clinical team has grown significantly in recent years and now provides a mix of specialist assessment, symptom management, service coordination, hands-on specialised nursing and ongoing skilled care to an ever-widening group of patients.

With the transfer of the Beacon Service to PTHC, we took the opportunity to review and strengthen our Clinical Management team in order to ensure the best possible patient-focused service, and now have a strong team with the skills, flexibility and leadership qualities to both drive the different services forward and assess patients' symptoms in more depth if required. This strengthened team continues to develop links and work with external partners to reduce unscheduled admissions to



hospital and enable patients to remain at home for EoL care if they wish. We are pleased to report that in 2016/17, 92% of our patients achieved their preferred place of death.

Our Outpatient and Day Services allow patients who are living at home to see a number of healthcare professionals during the same visit to either the Hospice or Beacon Centre. These patients are also offered

Group Work such as Wellbeing Workshops, an Art Group, and Social & Therapeutic Horticulture sessions. Wellbeing Workshops improve patients' and carers' ability to cope with and manage their disease, while the Art Group provides a positive activity completely removed from the patients' illness and the Social & Therapeutic Horticulture group helps to reduce stress levels, restore energy levels, and improve wellbeing and quality of life. All of these group activities attract some patients who may find the concept of attending a hospice daunting.

A recent key priority has been to make our services available for patients with conditions other than cancer, and we have seen a steady increase in the number of these patients, with 36% of Day Hospice patients and 24% of the Community team's patients having a non-cancer illness.





#### Support for families and carers



We recognise that children have their own specific needs and fears following the death of a significant adult (parent, grandparent or guardian) and this is where our Patient & Family Support (PAFS) team can help. Our Child and Family counsellors and psychologists work with parents and guardians to help them to understand their own fears, and prepare them to support the children in their care. They offer 1:1 counselling as well as couple and family support, either in the family's own home, at the Hospice or at the Beacon Centre.

We will, where invited, also work directly with the

child's place of education, offering support, guidance and resources to ensure they are appropriately and sensitively supported and cared for there.

We also run a bereavement support group specifically for teenagers ('Storm') as well as one for younger children ('Little Rays'). New volunteers were recruited last year so that the frequency of these groups could be increased.

### **Education and training**

Our clinical team promotes best practice by providing advice, training and guidance to other healthcare professionals (e.g. GPs, district nurses, care home staff and paramedics). We also participate in the NHS medical training programme and have earned a good reputation

for training doctors who are working towards becoming GPs (ST2) and Specialist Registrars (SpR), as well as providing regular training and support



to visiting doctors, nurses, therapists and pharmacists.

Our rolling programme of internal education for staff includes practical updates as well as ethical discussions. Degree master modules were achieved by members of the Community team during the year and articles written by our Clinical team were published in national peer-reviewed journals (e.g. Nursing Times, European Journal of Palliative Care and Palliative Medicine).

Underpinning all of our clinical services is a robust Quality & Audit programme which reviews efficiency and effectiveness across PTHC and encourages the involvement of clinical staff to review and critique their working practices.





We continue to support more patients, with a 2% growth year-on-year, and are now supporting over 1,900 patients in our catchment area, with a view to increasing this further. Our achievements in integrating the former Beacon Service into PTHC won us a national award at the Hospice UK conference, and recent Care Quality Commission (CQC) inspections at both the Guildford and Farnham sites have resulted in 'outstanding' and 'good' ratings for our services. We have worked with SECAmb (South East Coast Ambulance Service) to reduce hospital admissions, and now have the lowest conveyance rate to hospital in the area, and have implemented a more robust Lone Working procedure for both staff and volunteers, to provide additional security.

#### Community



Our Community team supported 1,693 patients during the year – an increase of 6% compared to 2015/16. In 2017/18 we will further develop these services, introducing locality management comprising a single point of access for all referrals, two geographical multi-disciplinary teams and a wider range of day services.



## Hospice Care at Home (HCAH)



Our HCAH Service supported 616 patients in 2016/17, a 6% increase from 2015/16. The recent expansion of this team has enabled us to provide this service overnight as well as during the day, and we have almost doubled the number of contacts made during the year, as well as reduced the number of unscheduled admissions to hospital.







#### In-Patient Unit (IPU)



Our IPU had its busiest year ever recorded, with a total of 420 admissions, a 12% increase on 2015/16.

Weekend admissions are now an established working practice, occupancy levels have increased to 83% and over a third of patients return home after their stay – reflecting the importance of respite care and symptom control admissions alongside terminal care.



## Patient & Family Support



Our Bereavement team saw a 7% increase in the number of people supported compared to 2015/16.

#### **Education**



Our Clinical Education strategy has been fully developed and the first year successfully implemented, and our End of Life and

Palliative Care courses achieved RQLE mark Award of Excellence from University of Surrey, with whom we work closely.



Recognising the Quality of Learning and Education

#### Research

We are increasing our involvement in research activities to improve care for patients, their families and carers, by understanding the needs of those we care for by exploring the different aspects of care – be it physical, social, spiritual or psychological. We now have a robust strategy and are actively participating in clinical trials and research programmes on a local and national basis.



"Once in your life you find someone who is special," says Mike. "And Yvonne was that." Mike had felt an instant connection with Yvonne. They shared a passion for travelling and during their 23 years together visited many places.

When she was 59, Yvonne was diagnosed with lung cancer, but an operation successfully removed the tumour and she remained clear. Two years later, however, as she was getting ready for work one morning, she told Mike that she was worried about her driving. He went with her and they set off, with Yvonne at the wheel, but as they reached the end of their road Mike had to reach for the handbrake, as Yvonne had failed to stop, or even slow down.

Tests confirmed that Yvonne had a tumour in her brain stem, which was preventing messages travelling from her brain to the rest of her body. She soon began to experience other symptoms too, such as numbness, confusion, memory loss and unsteadiness.

Yvonne underwent two operations to shrink the tumour, but eventually doctors confirmed it was terminal and referred her to Phyllis Tuckwell. She was visited at home by staff nurses Ruth and Julie, who offered her a bed on the IPU, but she declined, preferring to remain at home.

By June, Yvonne was bedbound and was being visited regularly by Hospice Care at Home (HCAH) nurses, who monitored her treatment and medication, and co-ordinated the team of district nurses and carers who also came to see her. "The whole thing couldn't have been better organised," says Mike. "I was amazed."

Yvonne's condition deteriorated rapidly and Mike began to struggle. Clinical Nurse Specialist, Kay, visited every week, caring for Mike just as much as for Yvonne. "I



said to Kay – 'you're coming to see me, you're always out here in the conservatory with me," says Mike, "and she replied 'you are the carer Mike, you're my main concern. I need to make sure you're well enough to look after Yvonne'."

Kay arranged for night nurses to visit Yvonne, and if there were any problems Mike would call Phyllis Tuckwell, where there was always someone available to give advice and support.

As Yvonne's illness progressed she became unable to talk, and communicated by squeezing Mike's hand. Mike would ask her a question, if the answer was yes, she would squeeze his hand in response. Eventually she was no longer able to support her body, and lay paralysed in bed. Mike continued trying to feed her with liquidised food and drinks of water, but she refused them all. Despairing that she was no longer receiving any nourishment, Mike suggested to Yvonne that she be admitted to the IPU. He held her hand and waited for a response - but none came. Yvonne's answer was not yes. She wanted to stay at home.

Not knowing what to do, Mike contacted Kay, who explained that Yvonne's refusal of food was part of the end of life process and that he wasn't doing anything wrong. Ten days later, she died peacefully at home – where she had wanted to be.

"I couldn't have managed it without the quiet confidence that Phyllis Tuckwell staff gave me," says Mike. "Kay was wonderful, and she visited right up until Yvonne died."





# Patient Stories: Nigel Lennard

"He was full of life and irrepressible, with a wicked sense of humour," says Vickie Lennard, whose husband Nigel died on our In-Patient Unit.

Nigel was referred to PTHC after being diagnosed with pancreatic cancer. He didn't want chemotherapy and our medical team respected his decision, offering him respite care to control his symptoms and doing what they could to help him, his wife Vickie, and their two sons Alex and Lorry, enjoyed the time they had left together.



"One of the most valuable things they did for us was pain control," says Vickie. "They understood that Nigel had serious pain issues, and suggested that he come into the Hospice for a week to see how they could help. Nigel wasn't keen to begin with - like a lot of people he thought that once you went in you never came out again! But I said that if we could get the pain under control, then let's do it. We came in for a week, and the difference it made was phenomenal. It meant we could travel, have weekends away, go and see people - we went to Italy, to France, and had some fantastic times - because the pain was under control."

"But towards the end the pain started to go downhill again. I remember the weekend before he came in for the second time - the pain was horrific. I phoned the Hospice at about three in the

morning and spoke to one of the nurses on the IPU. She was fantastic; she supported me and advised me on what medicines he could have. He went to sleep around six o'clock, but she said that she was still there on the end of the phone and to phone her back if I needed to. By 10am on the Monday morning he was in the Hospice again. They said 'come and stay with us, and let's get your pain sorted out'."

In the summer of 2014, Nigel came to the Hospice for the final time. "We were in a lovely room, with the gardens outside," Vickie remembers. "It was beautiful weather. The moment we got there, Nigel rallied. We had a couple of days where he was really feeling very comfortable, very settled. I'd spent so long nursing him that I said to the boys, 'this is it, we're just his family now; they can do the nursing.' It's so close to being at home and we were made so welcome. It made it much easier for our sons and family members to spend time



with him. Lorry was living nearby throughout Nigel's illness, so he could pop in whenever he wanted to, but Alex lived in Scotland at the time and he just couldn't bear to leave, so he and I both slept here for the best part of a week."

"If there's got to be an end of life, it's the best place to be. It allowed Nigel to die with dignity, which I shall be forever grateful for. If you can't die at home, I don't know anywhere better. Nigel felt the same. If he couldn't be at home, then he wanted to be here."







# **Income Generation**

We have successfully delivered our income generation targets for 2016/17, and have had particular success with Grant Making Trust funding.

New events, such as the Firewalk, Sailing Regatta and our Memory Meadow In Memoriam event in Guildford, have brought in more supporters, while well-established events continue to attract attendees.



We have carried out a comprehensive review of our supporter communications in light of new national fundraising requirements and developed new supporter care protocols for 2017.

Our Retail profitability continues to out-perform local hospices and other charities.

We have grown our digital engagement, resulting in increased use of digital marketing and donations.

We have also completed the roll-out of our 'Mission & Money' training sessions to all staff encouraging the whole team to work together to make the most of fundraising opportunities.

## **Fundraising Statement**

PTHC recognises the vital importance of securing and maintaining the trust of our supporters and donors. To this end we are focussed on striving to provide a high quality supporter experience. We believe that our supporters should have control



of their communications and feel secure in the knowledge that PTHC will not sell or pass their data to third parties. We do not engage third party professional fundraising agencies or buy data for marketing or cold calling purposes. Where third parties are used to fulfil our fundraising activities (e.g. mailing houses) we ensure that contracts are in place and that data is disposed of once fulfilment has taken place.

PTHC voluntarily subscribes to the Fundraising Regulator which assumed responsibility for regulating fundraising from July 2016. Prior to this we were subscribed to the Fundraising Standards Board (FRSB). Whilst we aspire to achieve the highest standards in our fundraising activities we are aware that sometimes things can go wrong. We aim to respond to all complaints within 24 hours and resolve them within 7 days.

PTHC adheres to the Fundraising Code of Practice and as such always takes into account the need to be aware of the needs of those who may be in a vulnerable circumstance or require additional support to make an informed decision. Staff are trained in how to deal with vulnerable supporters and how to identify when a donation may have come from a vulnerable person and how to verify whether the donation should be accepted.



# Income and expenditure



Our total income for the year was £9.9m, compared with £9.8m in the previous year. Whilst this is an increase of 1.3% for total income, there was a reduction of £0.3m (15%) in legacy income compared with the previous year. Excluding legacies there was an increase in income of £0.4m or 5.3%.

Total expenditure for the year was £9.6m, an increase of £0.6m from 2015/16. The community care contract which was taken on in April 2015 with the transfer of the Beacon Service to Phyllis Tuckwell Hospice Care, expanded further in the year under review and also had full year costs for some services taken on during the previous year. This accounts for an increase in costs of £0.3m (13%) in community care costs within charitable activities. 70p in every £1 is spent directly on our charitable activities.

Net income for the year before movement on investments was £0.3m. Gains on investments were £1.9m. Hence the increase in total funds for 2016/17 was £2.2m.

At 31 March 2017 the total funds of the charity were £20.5m.

## **Investments**

The total return on our two investment portfolios (including dividends) on the Growth Fund was 24.6% for the year ended 31 March 2017 and 38.6% for the last three years. The total return on the Income Fund was 18.4% for the year ended 31 March 2017 and 30.2% for the last three years. The yield on the income fund was 3.1%

# Reserves Policy

There is a Trustee-approved Reserves Policy in place, which will enable us to continue to deliver a full range of services following an unexpected fall in income. If income cannot be restored to previous levels, then services may have to be curtailed, but the Reserves Policy allows changes to be implemented in a planned way. The policy is reviewed each year and a target level for the General Reserve is calculated at the end of each financial year based on the approved budget for the next year, the general economic climate and recent trends in charity giving. The target for 2017/18 is £5.3 to 5.6 million which equates to 6.5-7 months of expenditure. At 31 March 2017 the balance in the General Reserve was £5.7 million.

# **Designated Funds**

#### We have three designated funds:

The Property Fund represents the net value of Tangible Fixed Assets that were purchased with unrestricted funds.

The Building Development Fund was established to accrue funds to assist with the costs of any new premises that may be required in the future.

The Service Development Fund provides financial backing for any new or expanded services.



2017/18 is the second year of our current three year plan. Our three-year strategic plan is documented separately and is available upon request. Our plans for 2017/18 include:

- 1. Remodelling our services to ensure they are responsive to our ever-changing healthcare environment. We plan to introduce locality working with two teams supporting the work of our external healthcare colleagues. based around the two major hospitals in our catchment area. and maintain a seamless service for patients and their families: set up an Advice & Referral Service for all PTHC referrals to provide one "point of access" for all referrals: and refocus our day services and ambulatory services by creating a range of 'Living Well' services.
- 2. Developing our support of non-malignant patients, following the appointment of our Nurse Consultant to work alongside our Non-Malignant Consultant.
- 3. Delivering an ambitious income generation plan for 2017/18, and building on the foundations for the successful delivery of the 2016-19 income generation strategy. We will also keep abreast of legislative changes and requirements, including the Fundraising Regulator, and ensure our response is proportionate and timely.
- **4.** Developing our approach to outcome measures (e.g. Outcome Assessment and Complexity Collaborative), and reviewing and responding to the Palliative Care Funding Review currency pilots.
- **5.** Continuing to develop our research activities to include staff training and the recruitment of patients into collaborative studies.
- **6.** Developing Key Performance Indicators reporting and information.

In our three-year strategy, we have set ourselves four strategic priorities:

## **Strategic Priority 1:**

We will provide - and be able to demonstrate - high quality EoL care services to patients and families in West Surrey and part of North East Hampshire.

## Strategic Priority 3:

We will generate sufficient funds to enable us to deliver our clinical services and demonstrate that we are good stewards of the money donated to us.

## **Strategic Priority 2:**

We will empower others to provide high quality EoL care and be seen as an authoritative voice at the decision-making table.

## **Strategic Priority 4:**

We will remain an independent organisation and demonstrate organisational efficiency and effectiveness.

For more details of our plans for these three years, please ask for a copy of our Three-Year Strategy (2016-19) document.

# Our Current Trustees, Officers and Contacts

## **President**

Mr E C Tuckwell

## **Board of Trustees**

Alan Brooks (Chairman)
Michael Maher (Vice Chairman)
Rosy Anand
Michael Bailey
Veronica Carter
David Eyre-Brook
Helen Franklin
Ken Kent
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# Thank you for your support!



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