

Progress

In this issue find out about ChangeTogether, our campaign to change the way people affected by pancreatic cancer are treated and cared for.



3. Annual Summit

The pancreatic cancer community comes together at our Inspiring Change in Care Summit.



4. NICE guidelines

First guidelines for pancreatic cancer will ensure highest standards of care.



8. Have your say

Take part in our patient survey so we can fight for better care and support services.



11. Pedal power

Join Kevin and our RideLondon-Surrey100 team to fundraise for us this July.

Up and coming

April 2018

Oxford Living with Pancreatic Cancer Day

Thursday 5th April, Oxford

We warmly invite you to join us for a supportive and informative day for people living with pancreatic cancer.

pancreaticcancer.org.uk/supportdays

October 2018

Royal Parks Half Marathon

Sunday 14th October, London

A run that takes you through the beautiful parks of central London and past its most iconic landmarks.

pancreaticcancer.org.uk/royalparks

November 2018

An Evening with Suggs and Friends

Thursday 1st November, London

Kicking off Pancreatic Cancer Awareness Month is An Evening with Suggs and Friends. We're promised another fantastic evening of great food, fun and of course fantastic entertainment, so save the date now. Tickets on sale soon.

Together for change

Since I joined Pancreatic Cancer UK, I've been struck by the incredible passion and determination shown by everyone in the pancreatic cancer community. That passion is key to taking on this tough disease, because the fight is far from over.



With 7 out of 10 pancreatic cancer patients not being given any kind of surgery, chemotherapy or radiotherapy, it is clear that we need to change the way that people affected by pancreatic cancer are treated and cared for.

Our Annual Summit this year is called **Inspiring Change in Care**. We know change is possible, we have seen it in other cancers. One such recent change is the launch of the first NICE guidelines for pancreatic cancer, a huge step forward in giving people affected by the disease the best possible treatment and care.

The session I'm leading at the Summit is called **ChangeTogether**. I'll be asking health professionals, scientists and people affected by the disease to share their ideas for how we can improve the way care is delivered and what they can personally do to make a difference. And we are asking them to commit to being part of that change.

We'll also be calling on supporters like you to tell us how you think care for people affected by pancreatic cancer needs to change. Check our website and social media channels for more details. **#ChangeTogether**

The more people that come on board with ideas and support us, the sooner we can make sure that patients get the care and treatment they need, when they need it the most. Together we can make this change happen and give people with pancreatic cancer a better chance of survival.

Thank you so much for your support.

A handwritten signature in black ink, which appears to read 'Diana Jupp'. The signature is fluid and cursive.

Diana Jupp
Chief Executive, Pancreatic Cancer UK

Changing lives through innovative care



Dr Derek Grose is Consultant Clinical Oncologist and Honorary Senior Lecturer at the Beatson West of Scotland Cancer Centre. At our upcoming Inspiring Change in Care Summit, Dr Grose will be talking about his research into neoadjuvant therapy. Here he answers a few of our questions:

Why did you want to take part in Pancreatic Cancer UK's summit?

One of the biggest challenges we face is the lack of awareness of pancreatic cancer among the public, healthcare professionals and policy-makers. Pancreatic Cancer UK is working hard to change that, so I was delighted to accept the invitation to speak at their summit.

What are you most looking forward to about the event?

Most scientific conferences are very niche, so this one is great because it's open to everyone affected by pancreatic cancer. I'm looking forward to talking about my work and the difference that innovative care and research can make to people's lives.

Why are new innovations in care and treatment so important?

Pancreatic cancer has one of the worst survival rates of any cancers and treatment options are very limited. New innovations are important because even a small improvement in care could have a dramatic effect on patients.

What improvements or innovations in care would you like to see realised in the next 5 years?

I would like there to be a clinical trial available for every patient. Only through trials will we be able to improve care, develop new treatments and stop people dying from pancreatic cancer.

Neoadjuvant therapy explained

Neoadjuvant therapy means giving someone a treatment ahead of their main treatment in order to make the main treatment more effective. It is already used successfully to treat some cancers however there is only limited evidence to support its usage in pancreatic cancer.

In a small clinical trial Dr Grose and his team gave patients with potentially operable tumours chemotherapy, and in some cases radiotherapy, before having surgery to remove their cancer.

And their results were very interesting. In some cases, the neoadjuvant therapy seemed to dramatically improve life-expectancy and in others, it had little or no effect.

Neoadjuvant therapy could still be a game-changer, but more research needs to be done to find out why it works for some patients and not for others.

NICE unveils new guidance for pancreatic cancer care

Following years of campaigning, we are thrilled to announce that the National Institute for Health and Care Excellence (NICE) has released national guidelines on the clinical care of pancreatic cancer.

The first of their kind for the disease, the guidelines are based on high quality evidence and outline the treatment and care that health professionals should offer patients to ensure they receive the highest standards of care. The guidelines also explain the need for effective pain relief and suggest ways to improve a patient's quality of life through nutritional support and psychological care.

One particular recommendation which is set to transform care is that people with suspected pancreatic cancer will receive the PET-PANC scan. This will improve diagnosis, offer more information on each person's tumour and show whether the cancer has spread. The PET-PANC scan also offers a vital second type of scan to patients whose first scan doesn't show enough information.

The need for more research into new, more effective treatments is also discussed in the guidelines. Recommendations include a call for larger trials to be conducted into neoadjuvant therapy, which you can read more about on page 3.

Pancreatic Cancer UK played a key role in shaping the guidelines. We made suggestions about its scope and, after speaking to people affected by pancreatic cancer and health professionals, we provided a response to the consultation on the draft guidelines.

Our Director of Operations, Anna Jewell, also sat on the committee that developed the guidelines as a lay member. Anna made sure

the patient's voice was heard by using the knowledge and experience she's gained at Pancreatic Cancer UK to talk about the impact the cancer has on people's lives.

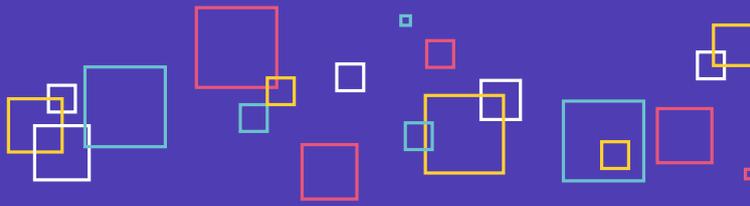


The fight against pancreatic cancer is a long one, and it's not over yet, but these guidelines do represent real progress. They will help reduce variations in care and ensure that people with pancreatic cancer in the UK get the treatment and support they need to live long and well.

"Pancreatic cancer is difficult to detect early and can spread rapidly. However multidiscipline treatment, which includes chemotherapy and sometimes radiotherapy, is improving and has helped some patients live longer. It is therefore vitally important that all people with pancreatic cancer have the best possible standard of care available. The Guidelines are a major step forward to ensuring that happens."

Prof JN Primrose
Chair of NICE Guideline Committee

To read the full NICE guidelines on pancreatic cancer visit [nice.org.uk/guidance/ng85](https://www.nice.org.uk/guidance/ng85)



PROMOTING INNOVATIVE PRACTICE

Driving improvements in care through Promoting Innovative Practice

“Pancreatic cancer is tough to survive. Currently the only way to cure the disease is through surgery but, with more than 80% of patients diagnosed at an advanced stage, it’s not an option for most people. That’s why it’s vital that we take urgent action to improve the care and treatment of pancreatic cancer. If we don’t, the disease is likely to become the UK’s 4th biggest cancer killer in less than a decade.

Although there are many examples of great care, they are not always widespread. We hear time and time again how patients and their families’ experiences have fallen short of expectations. This is simply unacceptable - everyone deserves to have the very best care and treatment, no matter where they live or where they are in their cancer journey.

So, this Spring, we are launching our new initiative **Promoting Innovative Practice** to drive improvements in care standards and disease outcomes of all people affected by pancreatic cancer in the UK.

Working with the whole pancreatic cancer community, including patients, their loved ones, health professionals, policy-makers and researchers, Promoting Innovative Practice will help identify new developments in care and treatment that are changing the story for people with the disease.

Where we find examples of excellence, we will shine a spotlight on them and encourage other health practitioners to find out more. We will also call for them to be adopted across the NHS.

By improving care today, we can help more people survive pancreatic cancer and transform the future for everyone affected by it.”

Georgia Papacleovoulou



Georgia Papacleovoulou,
Policy and Intelligence Manager

Let’s take it on together

We need your help to tackle pancreatic cancer head on. If you’re a health professional, researcher, policy-maker or affected by the disease, please get in touch today and tell us about the new developments in pancreatic cancer that you’re working on or have heard about.

If you are a health practitioner, you can also share your work and educate your network through our Promoting Innovative Practice Education Fund. Find out more about Promoting Innovative Practice at pancreaticcancer.org.uk/pip or contact us at pip@pancreaticcancer.org.uk

The PanDA study: nutritional therapy helping people to live longer with pancreatic cancer

NHS
The Christie
NHS Foundation Trust

With funding from our Clinical Pioneer Awards scheme, dietitians at The Christie NHS Foundation Trust in Manchester are undertaking an exciting new project that could help improve the quality of life for people with pancreatic cancer - and ultimately give them more time with their loved ones.

The Pancreatic Cancer Dietary Assessment (PanDA) study focuses on giving patients nutritional therapy when it is needed. Pancreatic exocrine insufficiency (PEI), which is a common symptom of pancreatic cancer, occurs when a tumour prevents the pancreas from digesting food properly, and, if left untreated, can cause malnutrition and weight-loss. For patients with inoperable pancreatic cancer, PEI can be particularly devastating as it can prevent them from being fit enough to have life-extending chemotherapy.

Earlier research has suggested that pancreatic exocrine insufficiency replacement therapy (PERT) and nutritional support could help improve the outlook for pancreatic cancer patients after surgery. But its effectiveness in helping people withstand palliative chemotherapy has never been investigated before.

And that's what makes PanDA so ground-breaking.

Through PanDA, researchers and clinicians at The Christie want to identify patients with advanced pancreatic cancer who are showing symptoms of PEI and what are the best tests to use to diagnose them sooner, so they can start treatment for their symptoms earlier. Researchers also want to observe the effects

of nutritional therapy on their quality of life and their ability to undergo life-prolonging treatment.

If PERT and this nutritional therapy approach is shown to be effective, it could transform the way people with inoperable pancreatic cancer are treated. It could help them manage their symptoms better, be well enough for chemotherapy and spend precious extra time with their friends and family.



In the last issue of Progress we told you about our Future Leaders Academy. We are delighted to announce we've now awarded five PhD students as part of this programme at the Beatson Institute in Glasgow, as they investigate how pancreatic cancer grows and spreads. Sigrid Fey is one of those students:

"Pancreatic cancer is tough, but the challenge of finding new treatments is what draws me to taking it on in my research career."

For more information on the PanDA study, please visit pancreaticcancer.org.uk/research

Pancreatic Cancer Awareness Month 2017: the highlights

Last November we asked you to **Get Purple** and save lives in Pancreatic Cancer Awareness Month (PCAM). The response we received was amazing, and we can't thank you enough for joining us on Purple Alert. Here are just some of the achievements that you made possible:

YOU RAISED A MAGNIFICENT

£91,000

AS A RESULT OF OUR NEW GET
PURPLE FUNDRAISING CAMPAIGN

113 

parliamentarians
attended events across the UK

 Our videos featuring pancreatic cancer statistics were seen by over

200,000 people

Over **86,500**   

of you liked, retweeted, commented and shared our posts

We reached nearly
70 million
people
through more than
1,000 pieces
of media coverage

Our fundraising superstar

Hamish Blair took **moving it** to a whole new level when he pulled on his wetsuit and took on the ultimate swimming challenge.

In just four days, Hamish swam a whopping 24 kilometres - that's further than the English Channel crossing. He did it in an unheated, outdoor pool, with every stroke a test of his mental and physical stamina.

Completing his last length on World Pancreatic Cancer Day, Hamish raised over £9,000 in memory of his father James, who died from pancreatic cancer in 2005.

Thank you Hamish for being our fundraising superstar!



Have your say with our patient survey

We want to make sure that everyone with pancreatic cancer gets the help and support they need to live long and well. That's why we have recently launched a patient survey to find out more about people's experiences of the disease, and the information, support and care they've been given.

The survey takes just 20 minutes to complete and is open to anyone aged 18 or over who has been diagnosed with pancreatic cancer in the UK.

There are a range of questions, some relate to your treatment and others focus on the impact the disease has had on your quality of life. Everything you tell us will be treated in confidence - we won't even ask your name.



The information we collect through the survey will help us fight for better care and support services for patients and their families as well as further develop the services we promote.

Please complete our survey online today pancreaticcancer.org.uk/patientsurvey



Side by Side, it's run by trained volunteers, and it gives patients the chance to speak to someone who knows what they're going through.

Every Side by Side volunteer has first-hand experience of living with pancreatic cancer. They understand the feelings that people have before and after surgery, and, although they aren't able to answer medical questions or give advice, they can provide reassurance and a listening ear, helping people to feel less isolated or uncertain.

The support offered through Side by Side is given over the phone, with calls arranged for a time that suits the person using the service. It's completely free and all conversations are confidential.

This Spring, we are launching a brand-new telephone service for people diagnosed with pancreatic cancer who have had, or who are likely to have, surgery. It's called

If you, or someone you know, would benefit from Side by Side, please contact our Support Line on **0808 801 0707**. One of our nurses will take your details and a volunteer will be in touch as soon as possible.

Our regional reach

Thanks to the generosity of our supporters, we now have more staff working in communities around the UK than ever before. We have:

3 Community Coordinators

Out and about in Northern Ireland, the North West of England and the West Midlands, our Community Coordinators are the local face of Pancreatic Cancer UK. Andrea Kearns, our Community Coordinator in Northern Ireland says “I am privileged to be able to support those affected by this tough disease. No two days are the same; I’m involved with supporters, health professionals and policy-makers, and with the support of my colleagues, I’m determined to help increase survival rates.”

2 Regional Pancreatic Cancer Nurse Specialists

In Northern England and the East and Midlands, our two Regional Nurses use their expert knowledge to offer support and training about pancreatic cancer to the health professional community. They also provide face-to-face information and support to people with pancreatic cancer and their family and friends through our Living with Pancreatic Cancer Support Days, which give people the chance to meet and share experiences with other people affected.

Through these five people alone, we are reaching hundreds of people affected by pancreatic cancer every year with our support and information.

To find out more about the support we offer visit pancreaticcancer.org.uk/getsupport

Meet the volunteer: Karen Manby

As one of our Information Volunteers in North West England, Karen holds information stands in hospitals and clinics, giving patients, their families and health professionals support and information about pancreatic cancer.



Karen Manby (right) with our Community Coordinator Lynn Quigley (left)

“My role is very varied, and I’ve been really surprised by how busy our stands are at times and how many people have been affected by pancreatic cancer.

Some of the people I speak to just want the opportunity to share their experiences and others are after specific information, with a range of people in between. What is important as a volunteer though is that it’s not just the different literature you can refer people to when it’s needed, but all of the charity’s other resources, including their Support Line.

Having all of this information at my fingertips, as well as the training I’ve had from Pancreatic Cancer UK, means I feel I can do something useful and helpful (which of course is personally satisfying) for people with pancreatic cancer.”

If you would like to find out more about our volunteering roles, visit pancreaticcancer.org.uk/getinvolved



Paul Basham staff enjoying their PCAM celebrations 2017

Fundraise for us at work

Tired of doing the same thing day in day out at work and keen to do something for charity but not sure where to start? If that

sounds like you then Pancreatic Cancer UK is here to help - because this year we want as many people as possible to support us in their workplace.

Getting involved is easy and there are lots of different ways for you to help. You could nominate us to be your company's charity of the year, ask them to become a partner in Pancreatic Cancer Awareness Month or turn your office purple for Purple Lights.

Alternatively, you could put on smaller fundraising events, such as bake sales or sweepstakes. Large or small, regular or one-off, every event you organise and every penny you raise will help us change the story for people with pancreatic cancer.

To find out more about how you can make a difference at work this year, please contact Amy in our fundraising team on **corporate@pancreaticcancer.org.uk**. She's waiting to hear from you!

Doing something extraordinary this year?

If you've already secured your place in a sporting event this year, why not make it even more special by joining Team Pancreatic Cancer UK and pledging to raise money for our life-saving work?

When you join our team, you'll receive lots of fundraising tips, training advice and more. You'll also be able to stand out from the crowd in one of our purple vests. And, as you've already got your place, all we ask is that you raise as much as you can.

Everyone's reason for taking on a sporting challenge is different, but for many of people

it's a way of remembering a loved one who has passed away from pancreatic cancer. If you would like to do your event in memory of a friend or family member, we can help you.

"By running, cycling or taking on another challenge of a lifetime for Pancreatic Cancer UK this year, you'll be at the heart of our community. Pancreatic cancer might be tough but together we're even tougher. Please join our team today."

Marianne Beggs,
Head of Mass Market Fundraising

For more information about joining Team Pancreatic Cancer UK in 2018, please visit **pancreaticcancer.org.uk** or call our events teams on **020 3535 7090**.

Pedalling for Paul in Prudential RideLondon-Surrey 100

This July, Kevin Hockney will be getting on his bike and taking on the ultimate cycling challenge in memory of his friend Paul Morton.

“Paul had such a big personality. He really couldn’t do enough for people, always looking out for them and encouraging them to be the best they could be. Even though he died in 2016, I still think about him every day - his presence is always with me.

Paul passed away quickly after being diagnosed. It was a huge shock for everyone and many of us felt we didn’t get a chance to say a proper goodbye. After Paul’s funeral, I organised a remembrance lunch for his friends and family, so we could celebrate his life and share our memories of him. It was there that I promised his family I would take on RideLondon-Surrey 100 in his memory - but only if I could raise money for Pancreatic Cancer UK.

Thankfully they agreed.

I’ve taken part in RideLondon-Surrey 100 twice before, and I wouldn’t hesitate to recommend it to anyone who wants to take on a sporting event for charity.

It’s a closed route so there’s no traffic and the Surrey countryside is just lovely as you zoom past it on your bike. The support you get from the crowds cheering you on from the side of the road is something I’d never experienced before, not to mention the camaraderie that exists between the riders. It’s also great knowing that friends and family can watch you on the telly at home or track your progress online.

For me, this year’s RideLondon-Surrey 100 is going to be extra special though because I’ll be wearing a Pancreatic Cancer UK cycling jersey with Paul’s name on my back. Just thinking about crossing the finish line at the Mall, and raising money to help fight this horrible disease, gives me goose bumps.”

Kevin Hockney



Prudential RideLondon-Surrey 100

When: 29th July 2018

Where: Begins at Queen Elizabeth Olympic Park, London, winds through Surrey & finishes on The Mall, London

Registration fee: £50

Fundraising target: £700

Perks of joining our team:

- Support from our training expert
- A team members’ training day
- An exclusive team cycle jersey
- Dedicated fundraising and training support
- A fundraising pack
- Loudest cheering point on the course
- Post event reception

To join Kevin and the rest of our RideLondon-Surrey 100 team this July, sign up at pancreaticcancer.org.uk/RideLondon

Coping with fatigue

People with pancreatic cancer tell us regularly that fatigue is a common symptom of their cancer. That's why we have launched a brand-new section of our website that's dedicated to helping you cope with it better.

Online you can find information on the causes of fatigue, how it can be managed, and the support that's available. You can also download our free fatigue diary to help you keep track of your fatigue.

Find out more on our website at pancreaticcancer.org.uk/fatigue

Two minutes can change our future

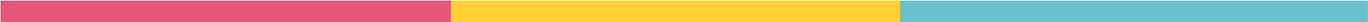
Thank you for supporting Pancreatic Cancer UK in the past. It means a lot to us because together we are taking on pancreatic cancer.

Did you know there are new privacy regulations coming into effect? This is good news for you as it can help you reduce unwanted communications. However, this could put your relationship with us at risk as from now on we can only communicate with you if you update your contact details and let us know you are happy for us to stay in touch.

Two minutes is all it takes to let us know how you would like us to remain in contact with you. Update your preferences today at pancreaticcancer.org.uk/contactme.

As someone who cares about changing pancreatic cancer outcomes we know you'll understand how important taking this action is for us.

Read our updated Privacy Policy
pancreaticcancer.org.uk/privacypolicy



Pancreatic Cancer UK

Pancreatic Cancer UK

6th Floor Westminster Tower
3 Albert Embankment
London SE1 7SP

020 3535 7090
enquiries@pancreaticcancer.org.uk
pancreaticcancer.org.uk

 [/pancreaticcanceruk](https://www.facebook.com/pancreaticcanceruk)
 [@pancreaticcanuk](https://twitter.com/pancreaticcanuk)

Connect with others in our **Forum:**
forum.pancreaticcancer.org.uk

Talk to a specialist nurse via our **Support Line:**
0808 801 0707 (Freephone)
nurse@pancreaticcancer.org.uk
