

FUNDRAISER PACK

How to set up a fundraiser



Starting a fundraiser on any scale is an amazing contribution and we are eternally grateful for every single effort towards Jon's treatment.

All funds raised go directly into the medication pot and make a significant improvement to the duration of treatment we can afford.

Our power to resonate with a wider network rests within all our friendships, families and communities that offers an incredible amount of people power for positivity!

Finding an idea that fits yourself and community can be overwhelming so here are some ideas and past successful fundraisers carried out by friends and family in the past. Feel free to use any and put your own wonderful spin on them! If you have any suggestions please contact us to let us know using the website contact form and we assist with getting the word out.

- Walk
- Bike ride
- Raffle
- Cake sale
- Car wash
- Sports tournament
- Card game
- Online games tournament
- Challenges
- Charity auction
- Music event
- Music release
- DJ stream
- Scavenger hunt
- Quiz night
- Art auction
- Music release
- Social media posts
- Food eating challenges
- Toy sale
- Running race
- Photo contest
- Car boot
- Pub, restaurant or venue donation jar
- Beach clean

FUNDRAISER IDEAS

Setting up your Fundraiser

So, you've got your idea for your fundraiser! Here's a guide to setting it up using GoFundMe, including how to set up your fundraiser so that the money will go straight into Jon's treatment fund savings account.

Setting up a Go Fund Me is simple and can be done in under an hour!

Setting up your fundraiser

- 1.** Go to <https://www.gofundme.com>
- 2.** Select "Start a Fundraiser"
- 3.** Set up the Go Fund Me on behalf of a beneficiary. [Download the photo pack](#) to use for your fundraisers images. See page 4 for example text to use for your fundraiser.
- 4.** Continue with the set up process. You will be prompted to fill in some details, it is very clear.
- 5.** When you complete the set up process, you will be taken to your dashboard.
- 6.** Click on "Transfers".
- 7.** Select "Someone else's bank account".
- 8.** Confirm your email address and move onto step 2.

Use the following details -

Tony Ward
tony.ward3006@gmail.com

Official Go Fund Me support resource can be found here for anything you get stuck on:

<https://support.gofundme.com/hc/en-gb>

Inspiration from our previous fundraisers can be found here:

<https://fightforward.uk/fundraiser-ideas/#fundraisers>



Example text for your Fundraiser

Explain your relationship to Jon (this may be through Jon himself, Bryony, Alex, Valerie or Tony).

I am raising money for Jon Ward's cancer treatment fund.

Jon (42) needs your help and he needs it fast. He is fighting for his life against the cruel, aggressive and highly lethal disease which is Pancreatic Cancer (Stage 4).

Pancreatic Cancer without targeted treatment currently has one of the highest mortality rates of all cancers.

Jon was diagnosed in June 2023.

The primary tumour was removed in August 2023 via a HUGE open surgery on his abdomen, called a Whipple Procedure. He thought he was out of the woods.

His entire world was ripped apart in November 2023 when a scan revealed that the cancer had already spread to his liver, despite the surgery.

He has endured 8 months of chemotherapy on the NHS to try and control the tumours. During his chemotherapy treatment, Jon endured immuno-suppression induced sepsis, depression and blood clots, lifelong medication (blood thinners, pancreatic enzymes) and scaring, with months of excruciating pain from his Whipple Procedure, teamed with opioid withdrawal from the amount of pain medication he required during recovery.

The disease has been slowly ripping Jon's life from him - friendship, love, ambition and music was replaced with terror, fatigue and crippling overwhelm.

Despite the gruelling nature of the past 10 months, Jon has kept remarkably fit. He has been walking, talking and laughing most days with his fiancé Bryony (28). He has also maintained a carefully crafted diet to promote healing and combat chemotherapy toxicity. Jon's family, particularly his his fiancé (Bryony), Mum (Valerie), Dad (Tony), little brother (Alex), and friends have been a vital source of support, grounding and laughter throughout this intensely difficult time. Jon would like nothing more than to create a life with Bryony.

In April 2024, the NHS determined that the chemotherapy was ineffective (as the tumours were still growing - albeit slowly).

Jons treatment was therefore suspended by the NHS.

This was a devastating decision which was imposed upon Jon against his wishes. So, Jon, Bryony, Alex, Valerie and Tony launched a campaign to raise funds to obtain private treatment abroad, offering genetically targeted treatment options.

Jon is currently undergoing this treatment at a private clinic in Germany and needs your help to continue his life-saving treatment plan.

Fundraiser tips

Here are a some tips that will help with raising donations and increasing the visibility of your fundraiser online.

- 1.** Post your fundraiser on social media at times of the day where people are more likely to be online. We have found that good times are between 12pm and 1pm (when people are on their work lunch breaks) and in the evenings between 5pm and 9pm (after work while people are still awake).
- 2.** Re-post your fundraiser post frequently.
- 3.** Thank you donors frequently.
- 4.** Post pictures of you with Jon and/or use pictures from fightforward.uk to give your donors a face to relate to.
- 5.** Be sure to use the “Share” function on the GoFundMe website to share your fundraiser. We have found that if you copy and paste the fundraiser URL, Facebook removes your post.
- 6.** Give your donors updates on Jon’s treatment. This may be by sharing Jons updates, sharing updates from FightForward’s Facebook Page or creating your own update from the information found on these sources.





Jon after his Whipple procedure , he lost 10kgs in weight in 2 weeks but was determined to make a strong recovery.

Jon's Full Story

Jonathan is 42 and his fiancé Bryony is 28. They met in June 2023 in the Royal Sussex County Hospital, in the A and E waiting room. Bryony doubled over in pain with Pancreatitis (unknown cause and healthy now) and Jon yellowing by the minute with jaundice (with unknown

cause, at that stage). They got chatting, exchanged numbers and were both admitted to hospital, to the same ward. They text 24/7, met up for walks around the hospital car park, cried to each other, shared their fears about their health issues, laughed together, shared life

stories and made jokes. They shared a connection of the cosmic kind, and had fallen deeply in love within moments of crossing paths, even if they hadn't admitted it to each other yet.

After 1 week Bryony was discharged. But Bryony's and Jon's communication continued. Bryony found herself walking across Brighton from her shared student house to the hospital to visit Jon during hospital visiting hours. Another week passed and Jon received the news that he had a growth on his Pancreas, and it needed to be removed as soon as possible. The word "cancer" was uttered briefly by the hospital staff to Jon, as a possible cause of this mysterious growth. Jon and Bryony spoke about this possibility briefly, and dismissed it. To them, this growth was a benign entity which was going to be removed for convenience. Despite a general feeling of unease, the severity of the situation was dampened by the fact that they were pleased that this growth was going to be removed - "That would be the end of that".

Jon was discharged after having a stent put in place (in his biliary duct to stop the growth from blocking it - the cause of his jaundice) after spending 3 weeks in hospital. He had lost weight since meeting Bryony, and was taking opioids for the pain which the growth was causing. After his discharge and his ordeal, Jon and Bryony continued to meet, their romance blossomed and within 6 weeks they were officially a couple. During this special time they realised that the bedroom Bryony was staying in at the time, was in fact Jon's best friend James Dean's old bedroom (over 10 years ago). James passed away from cancer at age 37 - may he Rest In Peace. Despite the poignancy of this coincidence, Bryony and Jon found comfort and beauty in it.

Jon's operation to remove the growth on his Pancreas was booked in for the 14th August 2023 at the Royal Surrey County Hospital. Bryony met Jon's parents for the first time as they collected him from Brighton to take him to the hospital. The operation is called a Whipple Procedure and involves the removal of the pancreatic head, part of the stomach, part of the bowel, and gallbladder. It is a routine operation for the removal of pancreatic tumours, for the lucky 20% of Pancreatic Cancer patients who qualify for this operation (that is, those without metastases and otherwise healthy). The operation took 5 hours. A day after Jon's operation, Bryony travelled from Brighton to Surrey to stay in a hotel 3 miles from the hospital. She worked on her masters degree dissertation in the hotel room from 5am - 6pm, at which time she would run or walk to the hospital to see Jon during visiting hours.

She visited Jon every day post-surgery (his parents would visit in the morning, and Bryony in the evening). The first day after his operation Jon looked small and his skin was grey. His eyes were dull and vacant, and at one point he had 5 tubes keeping him pumping, including a nasal

cannulae (which ran down to his bowel!). He was half conscious a lot of the time, but as he started to regain his strength over the following days, he would sit and laugh together with Bryony and his parents. He had a 10cm scar across his abdomen and was in pain, on a liquid diet. He was discharged after 5 days. And arrived back to Brighton, bought back by Valerie and Tony (Bryony was waiting in his house - cleaned and stocked with healthy food ready for his road to recovery), 10kg lighter (he was already slight in frame). He had to take Oramorph and codeine round the clock and Pancreatic enzymes with every meal. He officially stopped working as he did not have the physical or mental capacity to do so. Jon has his own graphic design agency which he worked hard to build over 13 years and it was a difficult decision for him to place his work on hold for (what we thought would be) a 6 month period. During his recovery, Bryony and Jon still found time to let their new found love blossom, as the leaves turned orange and autumn closed in. Bryony nursed him and they were happy - "the growth" was no longer a problem - it had gone.



In September 2023, Jon had a meeting with his surgical team which he attended with Valerie and Tony - they were informed that growth that had been removed was cancerous and had spread to his lymph nodes, which had been removed during the operation. Luckily, the post operative scan showed that the cancer had not spread anywhere else. However, we were warned that the scan would not show any growth under 1mm, so it would be best to begin preventative chemotherapy for 6 months. Although the thought of starting chemotherapy and enduring its side-effects was not exactly what Jon and Bryony had in mind for their new love, this disappointment was counteracted by the fact that the cancer had in fact gone, and had not spread. This chemotherapy was just a "flush". So they entered the next phase of their journey with trepidation, but had an overarching sense that we were out of the woods - they just had to get through the next 6 months and then we would be in their sunshine place, and could really get started on their life together.

Jon's chemotherapy started November 2023. Bryony and Jon attended the hospital for his first infusion together, armed with flasks of tea, distractions and their child-like, infatuated energy. Jon's first chemotherapy infusion did not go smoothly. He had a severe reaction to one of the drugs in the chemotherapy cocktail - increased heart rate, palpitations, sudden onset headache. He therefore couldn't complete the first infusion of his therapy. Jon and Bryony were reassured that reactions are common. The second infusion ran a better course and the drug which was suspected to have caused the reaction was omitted from his chemotherapy infusion. Bryony nursed him when they returned home. One evening she took his temperature

because he was shaky and clammy and pale. His temperature was up. She immediately called the hospital and rushed to A&E. He was admitted with sepsis. His next chemotherapy treatment was placed on pause. While he was in hospital, he had an MRI scan. Jon was soon called to a meeting with his surgical team at Surrey after his discharge from Sussex and his infection had gone. Jon, Valerie, Tony and Bryony attended. In the meeting the surgeons showed them the MRI scan. A black spot on his liver. They said it could be an abscess (a cause of the infection). It could be a tumour. Jon was to have a CT scan in 1 week after the infection had cleared, to determine what the dark spot was.

In December 2023, Jon had this all-important scan. He was terrified and strong. Bryony, Valerie, Tony and Alex were absolutely beside themselves - the definition of "worried sick". After the scan they were assured that the results would be relayed to them within 2 days. 2 days passed and no call. Bryony managed to get hold of Jon's surgical team at Surrey who gave news that the dark spot was in fact a tumour and there was more

than one. A wave of what can most accurately be defined as terror engulfed Bryony and Jon. They talked and cried a lot. They made the decision that they were going to fight. They spent sleepless nights researching about supplements, medicinal mushrooms and alternative therapies for what they now realised was "Stage 4 Pancreatic Cancer". In less than 3 weeks they had implemented a regime. A dietary protocol called the Gonzales Protocol, 15 mushroom supplements, 8 dietary supplements and hyperbaric oxygen therapy. Jon's chemotherapy was also resumed (a different cocktail of drugs, administered on a weekly basis), to be reviewed after 3 months. Christmas passed and Jon's hair fell out. The side effects of his weekly chemotherapy were taking their toll. He became fatigued and pale. It was hard to tell if the chemotherapy was healing him or making him more sick. Yet Bryony and Jon still found time to laugh, walk and talk most days. Jon delved into his passion - music. When he had the energy, he spent hours creating music from his bed or his office, and his creations became more tightly woven, beautiful and exciting every time.



In February 2024, it was time to review the progress of Jon's treatment plan. It was hoped that the tumours would have shrunk. But there was a mixed result. The tumour markers had started to drop. But the tumours themselves were growing. It was decided to continue with the current plan to establish a clear picture. Time flew, and in a blink of an eye, Valerie, Tony, Bryony and Jon were back in the consultation room in April 2024. It was bad news - the markers were rising and the tumours were growing (albeit very slowly). Worse news - Treatment was suspended as it was deemed ineffective because the tumours were growing, slowly. Clinical Trials at the Royal Marsden were offered, and declined because the success rate for such trials is "few and far between".

In a panicked state and after a conversation between Jon, Alex and Bryony, it was decided that the fight must continue. The net was cast net wide - There must be some place somewhere in the world which can offer a treatment for this evil disease. Bryony called and emailed doctors and private oncology clinics around the globe to investigate options - literally anything which held promise. The options were whittled down to 1 - A clinic in Germany offering genetically targeted treatment options, at a ridiculously high price.

In May 2024 Jon's fundraising campaign to raise £100,000. Jon's incredible network of friends, with the help of Bryony's family and friends and Valerie and Tony's generous long-time friends, banded together, reaching 50% of the target in 2 weeks. Alex lead the fundraising effort, inspiring and encouraging Jon's adoring friends to start fundraisers. Raffles, Club Nights, Sky Dives, Moon Walks, A cycle ride from Stonehenge to

Snowden (And climbing the mountain at the end), Cycling Races, Music releases, a sponsored martial arts "Kick-A-Thon" to name a selection. Alex was a powerhouse of energy and passion to save his brothers life. The money washed in and the family made the decision to leave for Germany as enough money to pay the deposit for the treatment initialisation was raised.

In late May 2024, Jon, Bryony, Valerie and Tony left for the Black Forest in Germany to the oncology clinic. Tony drove for 14 hours straight.

Bryony and Jon stayed for 3 weeks in the hospital. The oncology team tested the genetic mutations of the primary tumour (which was removed August 2023 during the Whipple Procedure), to decide what treatment to use. The results showed that Jon's tumour expressed mutations which are most commonly found in breast cancer, prostate cancer and stomach cancer (In addition to other mutations which are common to pancreatic cancer). The combinations of mutations in the tumour are very rare

which means it is extremely difficult to treat with standardised therapy, but the information also opened up avenues of treatment not usually associated with Pancreatic Cancer. This means that, in theory, drugs (immunotherapy, targeted chemotherapy, and radiotherapy drugs) which are used to treat breast, prostate and stomach cancer can be used to treat Jon, and have a chance of being effective. Unfortunately, the drugs are not licensed to treat Pancreatic Cancer in the UK. Financially and from a safety perspective, it made no sense try all of these drugs at the same time. So Bryony, Jon and the oncology team discussed what combination of drugs to use. A combination of 5 drugs was decided upon - 1 standard chemotherapy (typically used as a final resort treatment for pancreatic cancer), 1 targeted chemotherapy (typically used to treat breast cancer), 1 immunotherapy (typically used to treat stomach cancer), 1 tablet which blocks the blood vessels in the tumour and 1 cancer vaccine (a very new option, to target the breast cancer mutation that Jons tumour has).



In June 2024 Jon, Bryony and family returned back after treatment initialisation and took this information to Jon's UK oncology team. They were only able to provide the standard single chemotherapy component of the treatment plan on the NHS, which is also the cheapest drug. Due to the analysis that had carried out privately, a number of drugs that the NHS provides could be determined to be effective for Jon's Cancer. However when Jon requested for these drugs to be used in his treatment, the NHS denied access, as legislation determines that Jon has the wrong type of cancer for the drugs to be used. This was soul destroying for Jon to be told he would be sat next to people in the chemotherapy unit receiving the drugs he needs, for free, and that he was being denied that treatment due to red tape and will have to pay privately to access them.

Ultimately, Jon accepted the offer of the standard chemotherapy component of his treatment plan. The other 4 components of the treatment plan remain having to be funded privately. Jon, Bryony, Valerie and Tony have been and will continue to return to Germany to acquire these treatments, every 3 weeks (the length of Jon's stay is only 1 night now as the initialisation has been completed). This is Jon's treatment plan until approximately September 2024. At this point there will be a HUGE review and likely some treatment modifications. If the treatment is successful, Jon will continue on this plan (with some added extras further down the line), but will not have to go out to Germany every month. If it is not successful, there are back-up plans in place. These will need finalising with Jon's oncology team if/when this happens.

Jon and family are continuing their fundraising efforts, as the money will run out.



Jon at the Private Oncology Clinic having dinner while linked up to Chemotherapy treatments.



Burn that mysteriously appeared during Jon's Whipple operation, see next page for details.



Jon recovering after his Whipple Procedure in August 2023.

Our NHS Experience

During Jons NHS treatment, we have encountered a number of hurdles. We hope that by sharing, we can raise awareness and facilitate positive change in legislation and/or encourage more vigilant hospital standard practices.

- In May 2023 (prior to his hospitalisation in June 2023) Jon presented himself to his GP with shoulder pain, the GP attributed the pain to a pulled muscle. It was in fact Pancreatic Cancer. If Jon had been sent for a scan at that point, our situation may be entirely different.

- In June 2023, after his hospitalisation and after the growth had been seen, Jon was told that the growth "could be cancer". Jon was alone in a hospital bed when he received this news. He did not have the option to talk about this potential diagnosis with a consultant and have any questions or concerns listened to. He experienced panic while he was already feeling vulnerable and felt misinformed about his health issues.

- After his Whipple Procedure in August 2023, while still in hospital, Jon was given the news that a blood test had shown that he had an antibiotic-resistant infection. He was very briefly presented with a flyer with no explanation. He was put into an isolated room. It was then determined that the infection had been introduced via the stent which Sussex had put in place in June 2023 to relieve his jaundice. After discussion, the surgeon confirmed that the infected area was removed in the organs that had been removed and was no longer present.

- Two days after Jon's operation there was an issue with his pain medication machine. The staff who were on overnight duty did not know how to rectify this and Jon was left for 12 hours after his operation with no pain medication because the staff did not know how to fix the problem with the machine. This was rectified instantly when some more knowledgeable staff arrived in the morning. This was a duration of suffering which was completely unnecessary after such a seismic operation.

- In August 2023, Jon left his Whipple Procedure with a burn on his side from a heat pad. Jon was not notified of this after realising and received no treatment for this burn during his stay at the hospital instead cleaning it himself. This has left permanent scarring. See images. We understand that this was an accident but Jon did not receive an apology at the time, which is heartbreaking given his vulnerability. Care should be taken by surgical teams not to allow anything of this nature to happen to their patients.

- In December 2023, after Jons CT scan to determine if his liver lesions were abscesses or tumours, we were told that the outcome of the scan would be communicated to us within 2 days. We received no communication. Many hours were spent calling different points of contact at the Royal Sussex County Hospital to get the answer we so desperately needed. We had to call Jons surgical team at Surrey to obtain the answer. This process was distressing and unnecessary.

- In April 2024, Jons chemotherapy treatment was suspended because his tumours were growing. The rate of disease progression was slow though. Jon did not want to stop the treatment because although the treatment wasn't effective in the sense that the tumours had shrunk, the treatment was slowing the progression of the disease. After his treatment suspension, Jon underwent an 8 week period with no treatment, his disease progressed rapidly in this time.

- After seeking private treatment in Germany, we learned that a number of drugs available in the UK (which are currently used to treat breast, prostate and stomach cancer) could be used to treat Jon's cancer. Current legislation determines that these drugs cannot be used for Pancreatic Cancer, despite the genetic data indicating that they would be effective.



Web links

Go Fund Me Fundraiser page

All donations are made to this page.

<https://www.gofundme.com/manage/pancreatic-cancer-treatment-for-jon>

A Thousand Hundreds

A fundraising initiative to engage people that would share a post but not commit to start a fundraiser. If 1000 people can raise £100, by asking 5 people in their circle of family and friends, to donate £20, we can raise £100,000.

<https://www.gofundme.com/manage/pancreatic-cancer-treatment-for-jon>

Fight forWard website

The official Fundraiser resource for Jon's fight against Pancreatic Cancer.

<https://fightforward.uk>

**Fight
ForWard >>**

