



# Who we are

The Ellen MacArthur Cancer Trust supports, empowers and inspires young people in recovery from cancer through sailing. In 2000 Dame Ellen MacArthur DBE sailed with A Chacun son Cap, a French charity for children with cancer and leukaemia. Inspired by the incredible impact sailing had on helping them rediscover themselves in the confusing aftermath of cancer, and their courage, spirit and humour, Ellen launched the Trust in 2003.

## Frank's Foreword



I'm delighted to present this impact report providing a comprehensive insight into why the Trust is needed, what we do, how we work and our impact.

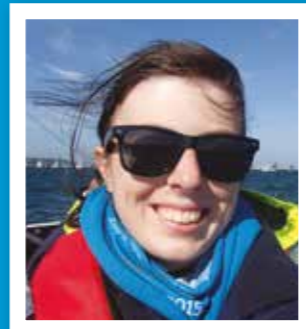
I've been personally involved with the Trust since it started in 2003, seeing us grow from taking 15 young people sailing in year one to more than 457 in 2015. In total over 1,513 young people aged 8-24 have sailed with us in our first 12 years.

When the Trust started we were not experts on young people's charities or cancer; we stumbled across a successful formula and have grown to a point where we have a real knowledge of the young people we work with and are confident we make a life-changing difference to them embracing their futures with optimism.

*Frank Fletcher*

Frank Fletcher,  
Ellen MacArthur Cancer Trust Chief Executive

## Meet Hannah



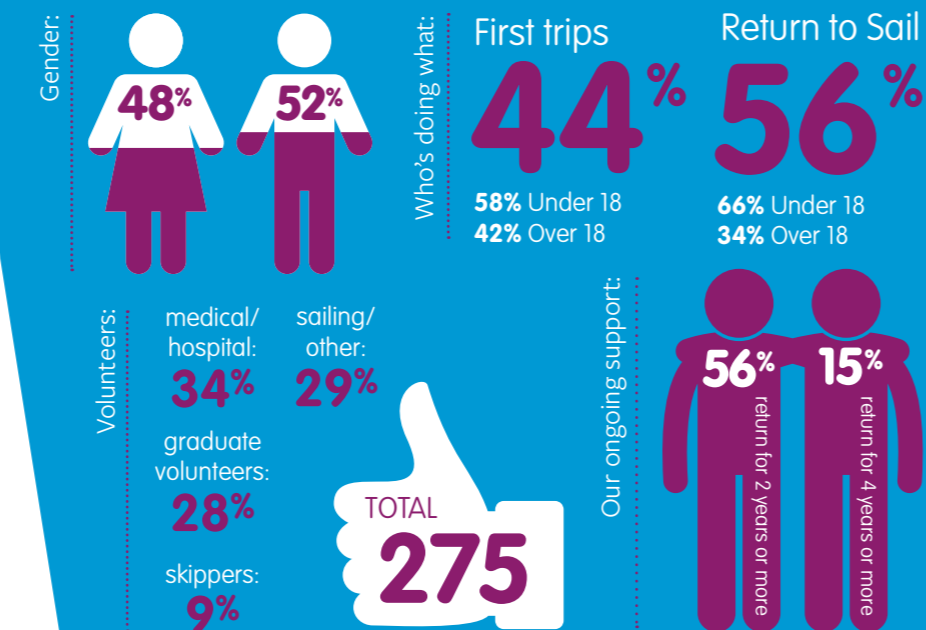
"I owe pretty much everything to the Trust for helping me build myself back up. They didn't push me if I wasn't ready but at the same time were like 'well you can have a go, can't you?'"

"Coming towards the end of treatment I started thinking about moving on. I looked at doing A-levels but didn't really fancy them. The Trust had helped me feel confident enough to question if I'm not into it then why would I do it?"

"I discovered there was a college just for animal care and successfully applied. The Trust has helped me make up my mind if I want to do something I'll do it, if I don't, I won't. I don't recognise myself from the person I was on treatment."

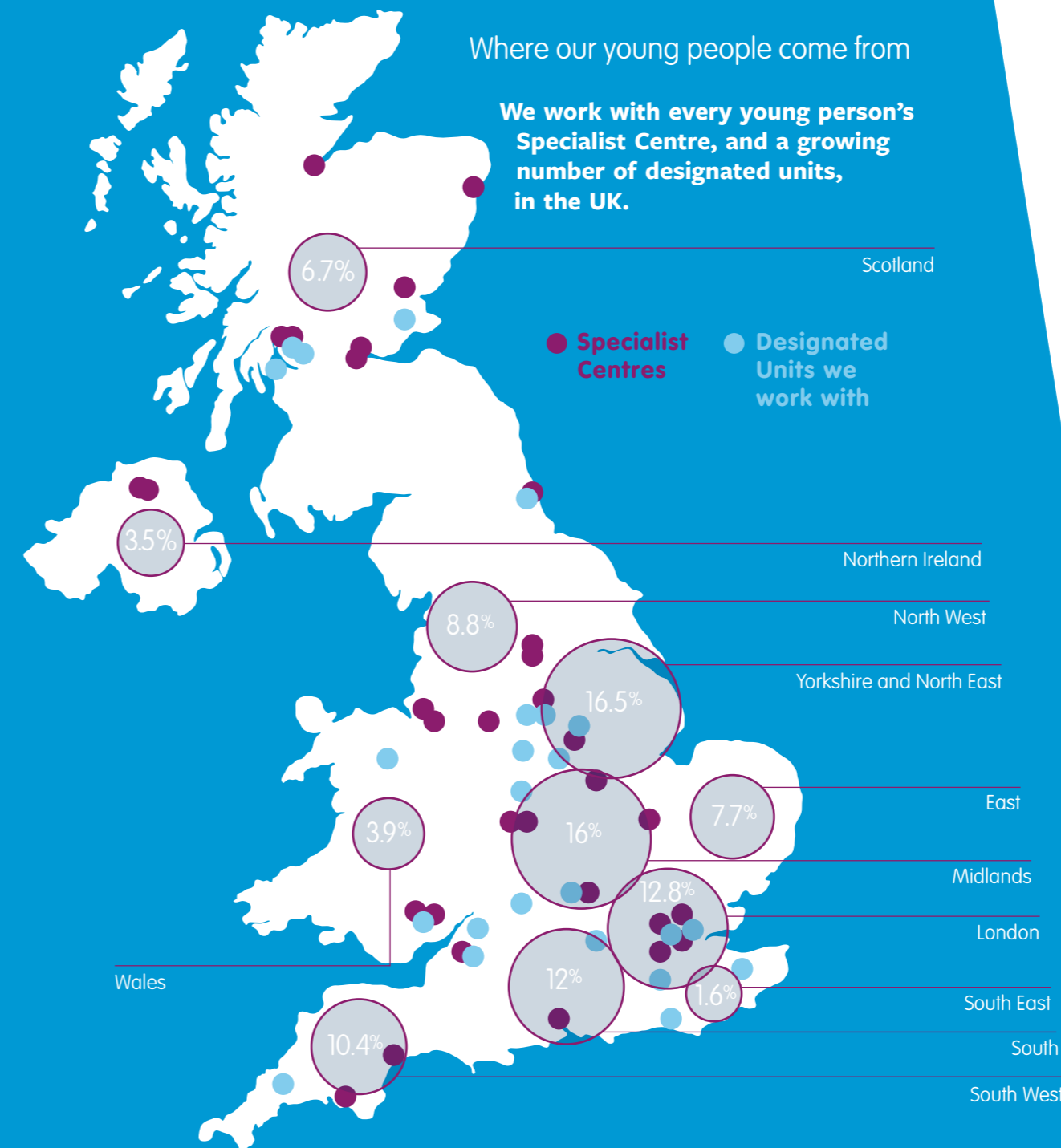
The Trust helped Hannah regain confidence after treatment for leukaemia including a bone marrow transplant. She first sailed with us in 2010.

## Who we worked with in 2015 (457 young people)



## Where our young people come from

We work with every young person's Specialist Centre, and a growing number of designated units, in the UK.



## The Medical View



Dr Dave Hobin, Paediatric Consultant Oncologist, Birmingham Children's Hospital, is a Trustee and medical volunteer.

"Every day in the UK, 10 children and young people are told they have cancer – 80% will be long-term survivors yet their cancer can have lifelong consequences."

"All young people endure many physical, psychological and social changes and challenges from adolescence into adulthood; developing independence, social networks and peer relationships, establishing their position in society and contributing to their communities. All this is threatened when cancer is diagnosed."

"Perhaps the most obvious impact of treatment is on body image, often affecting self-esteem and confidence, impacting on relationships and leading to feelings of isolation, fear and anxiety. Treatment can mean lost education time, which may negatively impact on goals and ambitions. Some will have permanent disability too."

"Providing opportunities for young people to rebuild their lives after cancer gives them the greatest chance to go on and achieve their goals and ambitions."

"The first step is rebuilding confidence and re-establishing self-esteem. Mixing with others who have had similar experiences is key. They start re-establishing peer relationships and provide mutual support. Realising they can participate in activities is often the start of the bigger process of recovery."



# Why are we needed – the context of cancer in children and young people

**In 2015 we took sailing 7.6% of young people in the UK in recovery from cancer. By the end of 2016, we aim for that to be 12% – more than doubled from 2013. Each year 2,800 young people (8-24) in the UK finish treatment. Happily survival rates are increasing – this means more young people than ever in recovery who need our help.**

**83%** of young people in the UK aged 0-24 receiving treatment for cancer go into recovery (approx. **3,400** of **4,100** diagnosed each year)

\* CLIC Sargent 'Counting the costs of cancer'  
\*\* CLIC Sargent 'No young person with cancer left out' (2013)

**90%** said cancer made them feel isolated\*

**74%** worried about impact of cancer on education\*\*

**66%** worried about impact cancer will have on future employment\*\*

**So why do they need us?**  
Survival rates are increasing. But while the wide-ranging medical implications of long-term illness are typically known with relevant support and advice available, there remains a chasm between treatment and young people re-discovering a societal normality. This is the gap the Trust fills.

When a young person is diagnosed with cancer everything else gets sidelined. 'Will they live?' is the only concern, getting the best medical care leapfrogs education, friends, work, relationships, independence, all else, as the major priority.

Life goes on hold at a time when young people are forming their place in the world. Studies show teens and young adults are particularly vulnerable because treatment comes at a time of rapid social and emotional development.

CLIC Sargent's 'Counting The Costs of Cancer' report (2011) highlights how young people (16-24) feel the cost of cancer is a price paid in terms of social and emotional wellbeing, educational progress and aspirations and expectations.

Evidence also suggests early illness can lead to fewer years' education, joblessness and lower pay in later life (Esposito, 2011) while Prasad found survivors of teenage cancer are less likely to have college degrees, work full-time, be married or live independently and were at higher risk of depression / anxiety (Reuters Health, 2015).



**“Never forget how much your work impacts our lives or belittle how powerful and beautiful your work is. I never, ever stop being thankful.”**

DEBBIE



## Education

Young people on treatment are more likely to fall behind in education, need special educational support and close monitoring for educational difficulties to maximize academic success (Barrera et al, 2005). Childhood cancer survivors have lower educational attainment than the general population (Lancashire et al, 2010), and chronic fatigue and attention / concentration issues can keep impacting on learning.

- 3/4** missed a lot of time in education\*
- 2/3** had fallen behind in studies\*
- 2/3** less able to study well\*

\* CLIC Sargent 'Counting the costs of cancer'  
\*\* CLIC Sargent 'No young person with cancer left out'  
\*\*\* CLIC Sargent 'More than my illness' (2010)



## Employment

A cancer diagnosis in young people has negative educational and vocational impacts longer term, including difficulties mapping out future career pathways (Stern, 1991). Teenage Cancer Trust research (2014) shows increasing a young person's job / career prospects contributes to positive mental health, and the degree of confidence a person has in their ability to work will increase the likelihood of being employed.

- 85%** said cancer has made them rethink what they want to do with their life\*
- 75%** said lack of confidence was a barrier to finding a job\*\*
- 61%** were concerned about how to disclose their cancer in a job application\*\*



## Emotional wellbeing

According to CLIC Sargent (2011) confidence and social and emotional wellbeing are increasingly recognised as playing a key role in life outcomes, while staying in education, employment and training is hugely important for emotional wellbeing as it can help young people picture a life after cancer and increase self-esteem. Young people on treatment are at greater risk of being excluded from social networks.

- 83%** missed their friends\*
- 46%** had not been able to meet someone going through the same thing as them\*\*\*
- 62%** unable to access a counsellor or psychologist, or needed more support\*





# Our approach –

Restoring young people's confidence after cancer

**Towards the end of their treatment a young person aged 8 to 24 can be referred by their hospital to come on their first four-day Trust trip. All young people face different challenges, but the desired outcome is the same for them all – confidence.**

In this safe, supportive and fun hands-on boat environment, friendships are rooted, physical and mental boundaries are pushed, independence is rediscovered, fears are overcome, new skills are learned, deeply personal experiences and worries are shared, often for the first time, being in hospital feels a world away and they laugh.

These trips are the start of a lifelong relationship a young person can choose with the Trust because we understand rebuilding robust optimism, self-esteem and self-belief in the aftermath of cancer cannot be achieved in four-days.

That is why our Return to Sail programme, and presenting opportunities beyond the Trust, are crucial as we appreciate a young person being able to picture a future and having the increasing confidence to live that future, getting involved with education, dealing with the challenges of employment, facing the realities of socialisation and relationships and just living a full, happy life, can be an ongoing process.

## Under 18 & Over 18 first time four-day trips



Graduate volunteer programme



Return to sail



Beyond the Trust

### ENVIRONMENT

#### Adventure Activities

- Sailing

#### Education

- New skills

#### Personal growth

- Self-achievement
- Overcoming fears
- Change in self-perception
- Feeling important

#### Increased Confidence

#### Increased Motivation

#### Socialising

- Being with others who have had cancer

#### Personal growth

- Decreased anxiety/relaxation
- Not feeling judged
- Decreased isolation
- Change in perspective on illness and life
- Increased positivity

#### Increased Confidence

#### Increased Motivation

### INCREASED INDEPENDENCE

#### Why does sailing work?

The Roberts-Bull Model of Enhanced Psychological Wellbeing (explored in-depth on pages 8-9) provides a useful insight into how the Trust has its impact.

Two primary interactions – adventurous activities and socialising – make a direct and long-lasting difference to confidence and motivation, reflected in what our young people tell us about the ways their trip(s) helped them. This cycle may be reinforced by taking part in additional trips offered through our Return to Sail programme.

We continue to learn from our young people what activities have the best outcomes and carefully plan our programme to promote personal challenge, skill development, socialisation, new friendships and fun.

Doing this in an environment where the young people know they are understood, where they don't feel judged, do not have to be anxious about what they look like or what they think they can't do, adds to the evidence that such therapeutic recreation is beneficial to psychosocial wellbeing and improved coping skills to seize their futures.

“This trip has made me realise I'm capable of much more than I give myself credit for.”



# Our impact – an independent review on the positive impact of sailing in young people's cancer recovery

**In 2013-14 University of Southampton Faculty of Medicine (Cancer Sciences: Child Health and Human Development) graduate, Jessica Roberts, with Dr. Kim Bull, conducted an unpublished study on 'Sailing as an intervention to enhance psychosocial wellbeing in children and young adults treated for cancer.'**

No studies had previously evaluated what sailing does as an intervention for enhancing psychosocial wellbeing, and the study's aim was to establish the extent to which the Trust experience positively impact on participants' lives.

The study's literature review determined that as the amount of young people surviving cancer is increasing, research is focusing more on their illness' psychological and social impact. Their psychosocial wellbeing may be adversely affected by cancer (Hedström et al, 2003; Wakefield et al, 2010), and the transition from patient to survivor may result in decreased liveliness and self-esteem and increased anxiety. The important phase of gaining independence, autonomy and self-confidence may be hindered (Epelman, 2013; Abrams et al, 2007).

Therapeutic recreation is an intended intervention to improve quality of life through recreation and leisure for children

with chronic and life-threatening illnesses (Martiniuk, 2003). Sailing produces and develops positive individual characteristics, such as leadership, self-esteem, feelings of control, attitudes and fitness (Hattie et al, 1997). On a boat everyone has a role and new skills may be developed, boosting confidence. The study highlighted how the small, physical boundaries of a boat was important in personal development, as it kept the young people more engaged. The level of teamwork in sailing is also a major differentiator (McCarthy, 2013), encouraging the young people to work with each other and catalysing friendship formation.

The study concluded young people benefited from their Trust experience in many ways and the Trust experience provides a challenging environment, facilitates social interaction and educational experiences, which positively enhances personal growth, motivation, confidence and independence.

## Digging Deeper

### Happiness

Participants noted a positive change in perspective on their illness and life with parents also observing enhanced personal feelings on their return home. The fun the trip brought was rated important, with many participants saying it was like no other experience they had ever had, being defined as life changing and a good escape from daily life.

### Socialisation

A shared understanding, having something in common to relate to, were mentioned most for feeling at ease around others, allowing discussions about medications / treatments plus feeling more open, comfortable and not secretive about health issues. Adult males appear to benefit most from the social aspect. Some said their communication had increased with friends and their social skills at home improved.

### Confidence

Parents and participants believed there was an enhancement in self-confidence, with participants saying this had come through a new awareness of their abilities and a change in self-perception with feelings of self-assurance and self-belief. Participants could challenge themselves and gain feelings of self-accomplishment.

### Additional trips

These allow ongoing friendships to develop as well as further opportunities to be around others in a similar situation. Parents said their child gains motivation as they have something to look forward to when they get a Trust invite. The social aspect – meeting up with old friends and new people and being around people who understand – was the most common reason for returning.

### Learning

The trip has valuable educational benefits, out-of-the ordinary learning experiences, and allows participants to practice new sailing skills, giving them a motivation to want to gain further experience and learn more on future trips.

### Independence

Parents' observations included their child being happy away from home and family and doing things on their own such as taking medication. Participants got a sense of normality and not feeling different.

## Key findings

The study analysed 173 2013 Trust trip feedback forms – 121 Under 18 participants and their parents and 52 Over 18 participants – against a framework of indicators for two paths of change – adventurous activities and socialisation. Thematic analysis of the data revealed social interaction was the most consistently mentioned theme by both age groups and genders. Other recurrent themes were personal growth, the environment, motivation, enhanced positive feelings and educational experiences.

### Positive impact:

- **68.4%** U18s and **78%** O18s said the trip had a positive impact on their lives
- **97.1%** of participants would have recommended the trip to a friend

**"All the things about treatment no-one at home gets, everyone gets here so you can be completely yourself and make friends who really understand."**

**"It has enriched my child's life experience and help to make her an independent, confident young woman."**

### Confidence:

- **86.4%** U18 and **92.2%** O18 years gained confidence
- **97.4%** of parents said their child had gained confidence

### Benefiting from additional trips:

- **41%** of participants said the social aspect was why they returned to sail
- **98.4%** of parents agreed their child had benefited from an additional trip

**"Each year my son looks forward to this trip more than anything else he does."**

### Skills:

- **96.6%** U18 and **92.0%** O18 gained new skills
- **99.1%** of parents said their child had gained new skills

**"He now knows if he puts his mind to it he can do anything."**

### Independence:

- **95.7%** of parents said their child had gained independence from the trip

**"Time away from the family has had a positive impact on our daughter; she hasn't had us watching her every move."**

### Friends:

- **95.8%** U18 and **95.5%** O18s gained new friends
- **96.5%** of parents said their child had benefited by gaining new friends

**"Everyone was so unfussed by physical appearances that my daughter gained a huge amount of self confidence."**



## Our 3 priority outcomes for our young people:

# 1

**Regaining confidence** – overcoming the struggle to maintain a sense of personal worth and regaining a control over their lives to feel happy and secure in themselves

# 2

**Improved ability to plan for a future** – moving from just being happy to survive, through dealing with survivor's guilt and understandable overreliance on parents/carers, to having the confidence to plan the next chapter

# 3

**Re-engaging with education/employment** – supporting the 66% and 74% worried about the impact of cancer on their education and employment prospects (see p4-5)

## Our impact – personal perspective



The Trust supports two age groups, 8-17 and 18-24 years, both facing different challenges but equally needing help in reigniting confidence for a bright future.

### Over 18s – embracing adulthood

In 2015 we conducted in-depth interviews with 12 over 18s who had sailed with us more than once to learn more about the Trust's impact on them as young adults. Issues raised included working out if and when to mention cancer, not wanting to get special treatment, working extra hard to prove capability and not letting any physical effects of illness impact on performance. Confidence, communication and ambition were important factors in overcoming these issues.

#### On employment:

**Abi:** "The Trust opened my eyes to what was out there, you meet so many people and I realised I could go and do anything I wanted, instead of looking at your school subjects and thinking 'I can only be this.' I wouldn't be a dietician if I hadn't got the confidence gained through the Trust. I speak to 20 different patients a day and if you don't have the ability to go up to someone and start talking to them you can't do the job. Meet me when I was 12 and you would never have thought I could do that."

#### On education:

**Tom:** (diagnosed at the start of GCSE year): "I carried on studying during treatment but dropped down to doing six GCSEs. I scraped by really but got enough to get me on to the next stage. I went to a local Sixth Form and just got what I needed from it. But in the gap before uni I went on my first Trust trip and it helped me have grander plans; I dreamt a bit bigger and had more ambition. I didn't want to just get what I could to scrape by for the next stage but to really push it. Now I'm doing a Masters."

**Wen:** (diagnosed in first year of university): "The independence I'd gained moving away was quickly swept away. I missed 18 months of uni and went on my first Trust trip just 10 days before going back. I was lost, nervous and no longer had the skills to make friends or the ability to do anything for myself. The trip changed everything. I returned to uni, made friends and although I had to take my degree part-time, I can now say I'm a graduate! This simply wouldn't have been the case without the Trust."

#### On the future:

**Tom:** "I sometimes think about what I'd be doing if I hadn't had cancer. I was predicted quite good grades so probably would have gone to a better uni and got a 'proper' job, with a suit! But then I think about where I am and I'm glad. The Trust's impact is a slow-burning thing. It planted something that's growing more and more. I don't think a lot of young people even think about employment or work when they come on the trips and I don't think they will realise before how much it does help."

**Abi:** "When I was on treatment I shut myself off and didn't want to speak to anyone. It was good to meet people and volunteers on the trips who were a bit older and were just cracking on with everything. It made me think 'yeh I want to do my GCSEs and do well' so I could be that person in the future. It spurs you on and gives you the motivation to get through it because everyone else is."

#### On survivors guilt:

**Claire:** "It was really difficult to accept my own survival and deal with the loss of close friends I'd met during treatment. I felt guilty for still being around as well as an enormous pressure to make something of my life. Instead of firing me up to study hard, see the world, and start a career, it paralysed me. The Trust trips helped me relax and have fun and eased a lot of that anxiety, I felt a lot calmer. Without the Trust I would have been crippled with anxiety and unable to fulfill my potential."

### Under 18s – the 'first trip' impact

Trust trips can have 'quick fix' and long-term benefits. Immediately after their first trip, we asked 112 under 18s to complete a short feedback form to see how they believed the trip had affected their confidence, schooling and approach to their own future. We also observed them during the trip to inform the study.

#### Where the young people perceived the trip had made a difference:

**64.5%**

helped in making independent choices and taking on new challenges

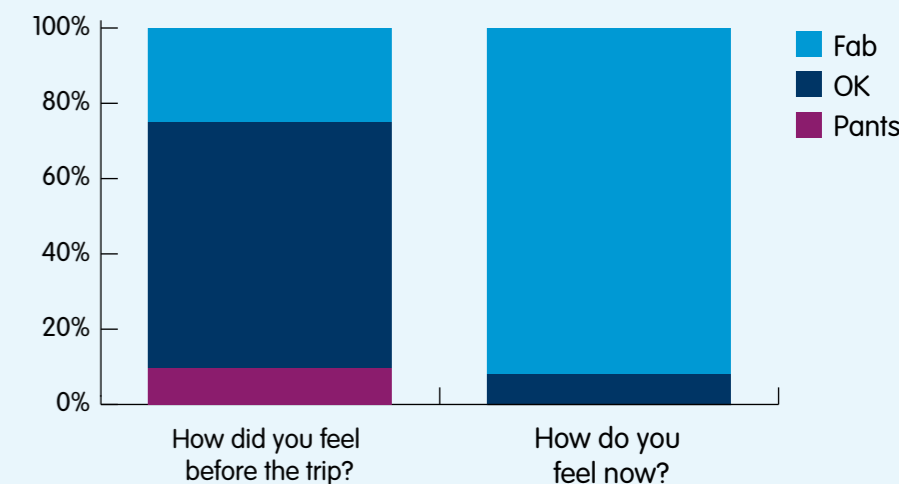
**37%**

helped make new friends and improved willingness to plan a future

**64.5%**

improved level of enthusiasm for school and level of optimism for educational/work success

#### How do you feel?



"I have proof I have some good qualities."

"I'm glad I came and will definitely come back next year."

"It has been the best experience of my life."

"A fabulous trip that made me feel happier and more positive about my cancer."

"This really helped me to come out of my skin and let my hair down again."

"I felt intimidated before I came because I've only been away from home a few times without family, now I feel more confident."



# Conclusion

A message from our founding patron



I hope you feel inspired reading about the work of the Ellen MacArthur Cancer Trust.

Having seen first-hand the impact sailing can have on a young person in recovery when I sailed with A Chacun son Cap, I am really proud to be here 15 years later reflecting on the incredible impact the Trust has since had on the lives of so many young people in the same situation throughout the UK.

I've honestly met more incredible people on our trips than anywhere else in life and I feel unbelievably privileged to continue to be a part of it. Every young person we have met has inspired us in a different way; that keeps driving us on to provide even more opportunities for even more young people.

Being on a boat, being away, having a group of young people living in the same space all sharing the same experience. I don't know how you could create that same atmosphere in any other way. I'm not even sure it's sailing, it's just the environment and the fact they all know what they have all been through. It just works; and we see it again and again.

If you are reading this report you either already support our work or are considering supporting us so thank you. Hopefully you now have a deeper understanding of the specific ways our work is able to make a difference, and help young people to look positively at their future prospects after cancer.

Dame Ellen MacArthur DBE

## Our approach to evaluation

**We can only keep doing the right things for our young people if we know, through all of our key stakeholders, including the young people, their parents, volunteers, staff and Trustees, what we do that works and what perhaps needs revisiting. Evaluation is key in understanding how to evolve the Trust in the young people's best interests.**

### What do we evaluate?

- Service quality – delivery
- Relevance – are we doing the right things?
- Outcomes – do we achieve our objectives?
- Relationships – how do our participants relate to us?

### How do we reach our stakeholders?

- trip feedback forms
- focus groups
- observation
- interviews – including 'deep dive' targeted information gathering
- social media boards
- unsolicited comment

### How else do we get information?

- external research
- working with other organisations (charities, hospitals etc) within cancer care
- working with adventurous activity specialists
- our funders – particularly relating to impact assessment and reporting

Much of our understanding is self-reported – a strength of the Trust is the relationships that are rapidly fostered between our young people, staff and volunteers. This is of real

value in us gaining honest insight and feedback as to the differences the young people feel, and that parents and other professionals, eg medical / social workers etc, tell us they see in the young people they care for.

The Trust Youth Board, established in 2013, also provides an invaluable link between the young people and Trustees. Its aim is to provide a more informal forum to gather trip feedback and identify what the young people really want from the trips.

In 2014 we appointed our first Trust graduate to the full Board of Trustees. Claire Amaladoss first sailed with us in 2007 after treatment for Hodgkins Lymphoma and co-founded the Trust Youth Board in 2013.

Claire was diagnosed in Year 8 at school, but went on to gain 11 GCSEs at A\* and A, graduated in development studies from the University of London's School of Oriental and African Studies and now works in government relations for an international charity. Claire brings her own personal insight of life after cancer to Trustee level.

## Meet Claire:

*"Suddenly I felt as if my future was clouded with uncertainty, like it could be taken away at any moment. I was afraid to make plans and dream big. This affected my motivation at school significantly. I couldn't see what I was working for anymore.*

*"I went on my first Trust trip aged 14 in the summer before I started my GCSEs. It was real game-changer. I saw another young person, Dan Monk, who had been through the same experience getting on with life brilliantly and skipping a yacht. Just four days on the water with the Trust restored a sense of possibility. I returned to school with a boost and threw myself into my GCSEs.*

*"Each summer for the next five years I returned to sail with the Trust. My confidence built and gradually, with the Trust's continued support, I felt increasingly able to imagine a future. I started thinking about university and moving away from home; something that wouldn't have crossed my mind previously. I had a full university experience including a year in Tanzania. If you had told my shy, anxious 14-year-old self this was possible I just wouldn't have believed it."*



**"Just four days on the water with the Trust restored a sense of possibility. I returned to school with a boost and threw myself into my GCSEs."**

CLAIRE



# Inspired to inspiration

## Dan's story

"I'm a strong believer in keeping your head up, thinking about the good things and you will get through. The Trust is what got me through."

**Dan beat leukaemia twice as a teenager. Having had treatment in 2001 he sailed with us in 2004, before relapsing a year later and going into hospital for a bone marrow transplant two days after sailing with us in the Round the Island Race.**

Dan's Trust experience led to him gaining his qualifications to become a Trust skipper and in 2007 he was appointed our first Trust Ambassador and competed in the Clipper Round the World Yacht Race. In 2015, exactly 10 years to the day since that first emotional Round the Island, he skippered a Trust boat in the race.

"I was laying in a hospital bed struggling to breathe, couldn't move, you lose lots of weight and your hair, everything's quite depressing. The bone marrow transplant could have been the last thing they could ever do for me. If my body had rejected the bone marrow there wasn't much else they could do. It was my last chance.

"I really believe the Trust helped save my life. While I was in hospital they gave me a chance to become a skipper; that gave me something to look forward to and the fight to keep on going. Every time I felt really down I thought back to when we were on the boat, it put a smile on my face and I looked forward to going again.

"Now helping other young people learn to sail and to say 'I was like you and now look where I am' puts a smile on their face, it's great they can see they could do the same. Having young people who have been through the Trust come back as volunteer boat mates and crew is a really important part of what the Trust does for this reason."



**Dan's story is one personal account. But every year the feedback we receive from the forms we send out after every trip reflect Dan's experience as this evidence from 2014 shows.**

### Quality of experience

How much did you enjoy your trip – **97%** loved it or was great



How much did your child enjoy their trip (U18s only) – **98%** loved or really enjoyed it

### Immediate difference



Parents of U18s agreed or strongly agreed their child benefitted from:

Gained confidence **95%**  
Gained new skills **96%**  
Made new friends **90%**  
Gained independence **96%**

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