success charity

2024

Conference Feedback

Successful Destinations







Brighter Futures For Childhood
Brain Tumour Survivors

These are only some of the wonderful comments you sent us after the conference - thank you all for all the support!

> Meeting people who understand where I'm coming from was amazing.

> I thoroughly enjoyed being part of this community

You can now find all of the videos from the conference on our website and via this QR code below

> The survivors' stories were amazing!

> Connecting with other mothers was just so helpful

> The mix of survivors, parents and experts was perfect

> It was so well organised and informative

> Incredible to see the commitment from all to improve care

> The experts' talks were fascinating

> Just meeting everyone! Amazing!

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From: Dr Helen Spoudeas

SUCCESS Chair and Founder

We were delighted to once again welcome some 140 delegates to The Royal Society of Medicine on 2nd March of this year. Our aim was to SHINE by fostering an environment where we could **S**hare, **I**nnovate, **N**etwork, and **E**mpower for the advancement of "Brighter Futures for Childhood Brain Tumour Survivors", and for the first time to also offer continuous professional development [CPD] to a variety of new hospital and community professionals supporting the recovery of children during and beyond cure.

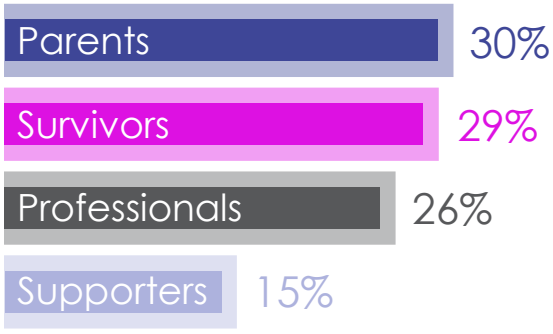
The conference was an opportunity for networking among patients, families, professionals, parliamentarians, and NHSE decision-makers to set standards for best practice, effect cost-efficient change, influence health policy and health service research to deliver on our aim: innovating transformational change in health care delivery and educating to improve secondary long-term health and quality of life outcomes over the next 5 years.

As always, survivors shared their stories, always inspirational and always reminding us that more is needed to address the challenges a childhood brain tumour causes – more help is needed for them to arrive at their successful destination.

Do join us in this journey and help us help them achieve a brighter future.

Helen

Conference Overview



140 participants, mostly SUCCESS beneficiaries, comprising **85%** of the group, and including a significant portion of professionals, met with key parliamentarians for a day filled with potential to **share**, to **innovate**, to **network** and to **feel empowered**.

Were you happy you attended?

Over 90% of you **agreed** and **strongly agreed** that attending this conference was valuable and worthwhile and that it addressed key objectives:

- Provided clarity on the importance of a parallel recovery path
- Improved your understanding of our aims and mission
- Made you feel more inclined to support us
- Made you feel more encouraged to support survivors





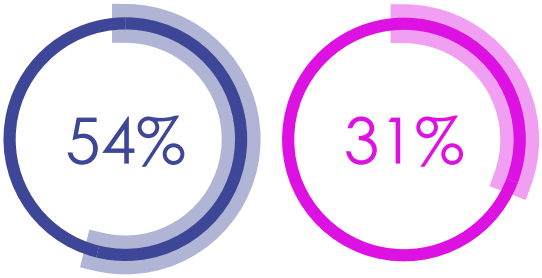


Overview cont...

What did you like most about our conference?

From a choice of five possible options you rated the following two as most valued:

- **better understanding of key challenges & how to find support for them**
- **inspiration and hope for the future**





We asked you to comment on the areas you particularly enjoyed as part of the conference.

Here's a few comments we gathered as part of the feedback.

Some of your comments...

"I enjoyed hearing other survivors' stories. I find those so fascinating

It was incredible to learn from the lectures given by the experts and professionals"

"Connecting with others is so valuable, sharing information and meeting other parents

The mix of survivors' stories and professional talks worked very well"

"The conference was so organised and informative

It was to see the commitment from medical experts to improve service"

"The whole event was so friendly and welcoming. It was like being part of a family

I loved meeting people who understand you, and with whom you can share the burden"

"I always find it very valuable to hear information about injuries to the brain

Our vision



Dominic Grieve KC
SUCCESS Patron

Where are we going?

"SUCCESS is transforming lives for the better. It is clear that we are making progress in an area previously neglected and are on the cusp of something exceptional - helping children recover their full potential after treatment for brain tumours.

National Recovery Pathway

Cure alone is not enough

Investments in cancer research have led to an 80% 5-year cure rate for children with brain tumours, but the toll on their development is often overlooked.

Our **goal** is to improve outcomes for childhood cancer survivors, including personalised treatments and rehabilitation.

To achieve this, SUCCESS advocates for the **SUCCESS Standard Survivorship Pathway** within the NHS.

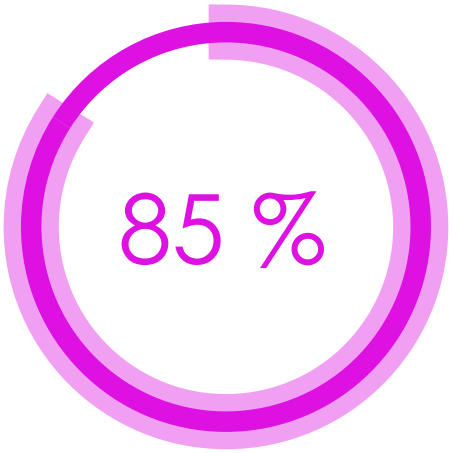
This pathway, tailored to tumour location and individual needs, would:

1. Start at diagnosis,
2. continue beyond cure, and
3. Support the transition into adulthood.

It aims to provide specialised care for all children with brain tumours, addressing their unique challenges.

We asked you how the charity can best help survivors and their families. This is what you told us:

Overwhelmingly, you told us that you wanted us to continue to **advocate for a parallel recovery pathway.**



Our vision cont...

Overview - National Recovery Pathway

From diagnosis of a **brain** tumour - for every child - two parallel **linked** treatment pathways

1 Cure Pathway
Inpatient Neuro-oncology Multi-disciplinary team (MDT)

Current treatment path including complete assessment, application of treatment plan, review of effects and support through adult transition

EXISTING TREATMENT PATHWAY

SUCCESS ADVOCATE Liaison with Pathway 1, support through recovery, ensure agencies understand, embrace and deliver discrete plan components

2 Recovery Pathway
Outpatient Recovery & Developmental MDT

SUCCESS PATHWAY

Complete baseline assessment, creation of initial holistic rehab plan, execution of plan, support across four key stages of development and on going review and assessment of outcomes.



Daniel Bell
Neurophysiotherapist
GOS Hospital

Evaluating the current state of rehabilitation

SUCCESS has commissioned a 9-month gap-analysis study at GOSH of survivorship service gaps against current national standards for survivors of brain tumours at set points during and after treatment.

Daniel provided a full and insightful early plan update as part of the conference before study completion in September.

"Given the minimal costs involved in providing full holistic recovery - **£2,000 per child per annum** – and the clear, significant long-term socio-economic benefit this would bring, it is no longer acceptable for survival to be the only measure of cure. It is incumbent on all of us to bring about change and to agree outcomes that show improved quality of life for survivors now and in the future.



Dr Helen Spoudeas
Chair and Founder

The Survivors' Voice

Our journey, our words

As always, the survivors' talks, and their courage in sharing their stories, took centre stage and provided a reminder of both the challenges they face and the resilience they have in overcoming adversity.

Laura Bailey

Listen to Laura's story

"I don't feel worried standing here, because I know that you know what it feels like.



When The Tumour is Cured and You Find Yourself Alone - Who Understands?

Laura is 39 and lives in North Wales. When she was 5, she was diagnosed with an incurable brain stem astrocytoma; after two brain operations and a course of radiotherapy, her parents filmed her sixth birthday fearing it would be her last. Listen to her extraordinary story of resilience, the challenges she had to face and the extraordinary way she managed to overcome them.



"It's hard to stand here - but I do it so that other children don't have to suffer the way I did.

Youssef Ghanem

Listen to Youssef's story

When The Cancer Hauntingly Returns - What Care is Missing?

Youssef was 5 when he was first diagnosed with a glioblastoma, a high grade cancer of the brain. 18 weeks of chemotherapy and a course of radiotherapy followed. He relapsed aged 13 and faced the difficult decision to undergo a 2nd round of radiotherapy he might not survive and which would further impact on his learning, and executive functions. He bravely chose life, of course, but at a significant cost which he feels strongly others, with better recovery programmes in place, should not have to face in the future.

Cont...

Olivia Harding

Listen to Olivia's story

"I hope we can help other children with tumours just like mine feel less scared about treatment.



When a Craniopharyngioma Proves Difficult

Olivia was diagnosed with a craniopharyngioma when she was 4 years old. Whilst benign, the surgery and consequences of its removal are just as invasive and often harder to completely cure. Her parents should not have had to fight so hard to be presented with less invasive, more effective surgical options, and they made a powerful case about the importance of choice and equity of access for the best possible care according to the new guidelines for pituitary tumours SUCCESS has championed and published



"We need better, more appropriate care, for children diagnosed with a pituitary tumour.

When a Tumour Produces Hormones - Are Pituitary Physicians Key to Care Across the Age Divide ?

Grace made a powerful case, by going through her own journey, about the need for more specialised paediatric care for pituitary tumours as SUCCESS is calling for . She spoke eloquently about her traumatic experience of being treated by a system not designed to provide for children and which took a long time to identify the cause of her symptoms - a familial / hereditary pituitary adenoma.

Grace Kearns

Listen to Grace's story

You can also listen to our survivors' talks via our website www.successcharity.org and access previous conferences talk too for more inspirational stories!

Expert talks

CPD

Our conference obtained CPD approval for those professionals attending

What did you think?

Overwhelmingly, the professionals assessed the overall usefulness of attending the event as **"extremely useful"** and their overall impression of the event and programme were **"excellent"**.

Experts Parallel Sessions

As part of the conference, over ten medical professionals and parliamentarians were actively involved across four different parallel sessions all focused on providing better highly specialist access for very rare pituitary tumours and better rehabilitative services for all survivors childhood brain tumours.

Specialist Pituitary Tumour Services

Launching our newly endorsed and published national multi-society guidelines for management of pituitary tumours

LEAD
Mr Simon Cudlip
Pituitary Surgeon

Specialist Education Services

LEAD
Dr Jane Williams
Consultant

Focusing on the rights to enhanced educational provision in the mainstream to all those with brain tumours

Hypothalamic Symposium

Focusing on the needs to better understand the diverse effects of this devastating midbrain hypothalamic injury which can occur from brain tumours

LEAD
Prof Darren Hargrave
Consultant

Survivor-led workshop: education

LEAD
Matt Tozer
Survivor

Workshop covering legal rights relating to accessing education and employment and how to best navigate the system

Expert talks cont...

"We know how survivors should be treated. We now have approved national guidelines. And if we can find a way, through the MDT advocated by SUCCESS to ensure all have equity of access to the right rehabilitation, then it is incumbent on the medical community to be supportive and say "YES!", this is what we want to do

Prof Darren Hargrave
Paediatric Neuro-oncology





"Breaking down barriers is important. I didn't have the right educational support and was very much "learning on the job" about what my needs were. Having a psychologist support integration into a working environment is key in ensuring long-term success

Matt Tozer - Survivor



Mr Simon Cudlip
Pituitary Surgeon

"The only sensible way to improve children's access to specialist care is through a national service for rare childhood pituitary tumours via bespoke commissioning of specialist centres.

"Centralisation of care is needed to develop expertise in pituitary tumours with multi-disciplinary national advisory groups for these unrecognised needs.



Dr Hoong-Wei Gan
Endocrinologist

Our Strategy



Debate: what more evidence would convince NHS England to commission Services

From left to right:
Lord Sandhurst KC
R Hon Derek Thomas MP
Dr Helen Spoudeas
Dr Jane Williams
Prof Darren Hargrave

Setting a successful course

The conference closed with a debate led by our patron Dominic Grieve KC on how to best effect SUCCESS survivorship hubs and commissioned pathways which deliver our vision of transformational change in the way health care is provided and thus improve secondary health outcomes.

You all agree!

When we asked you if we should continue to focus our effort in advocating for a parallel recovery pathway to improve the way health care is provided during and after treatment is finished, the majority of you agreed this is both a need and a priority.





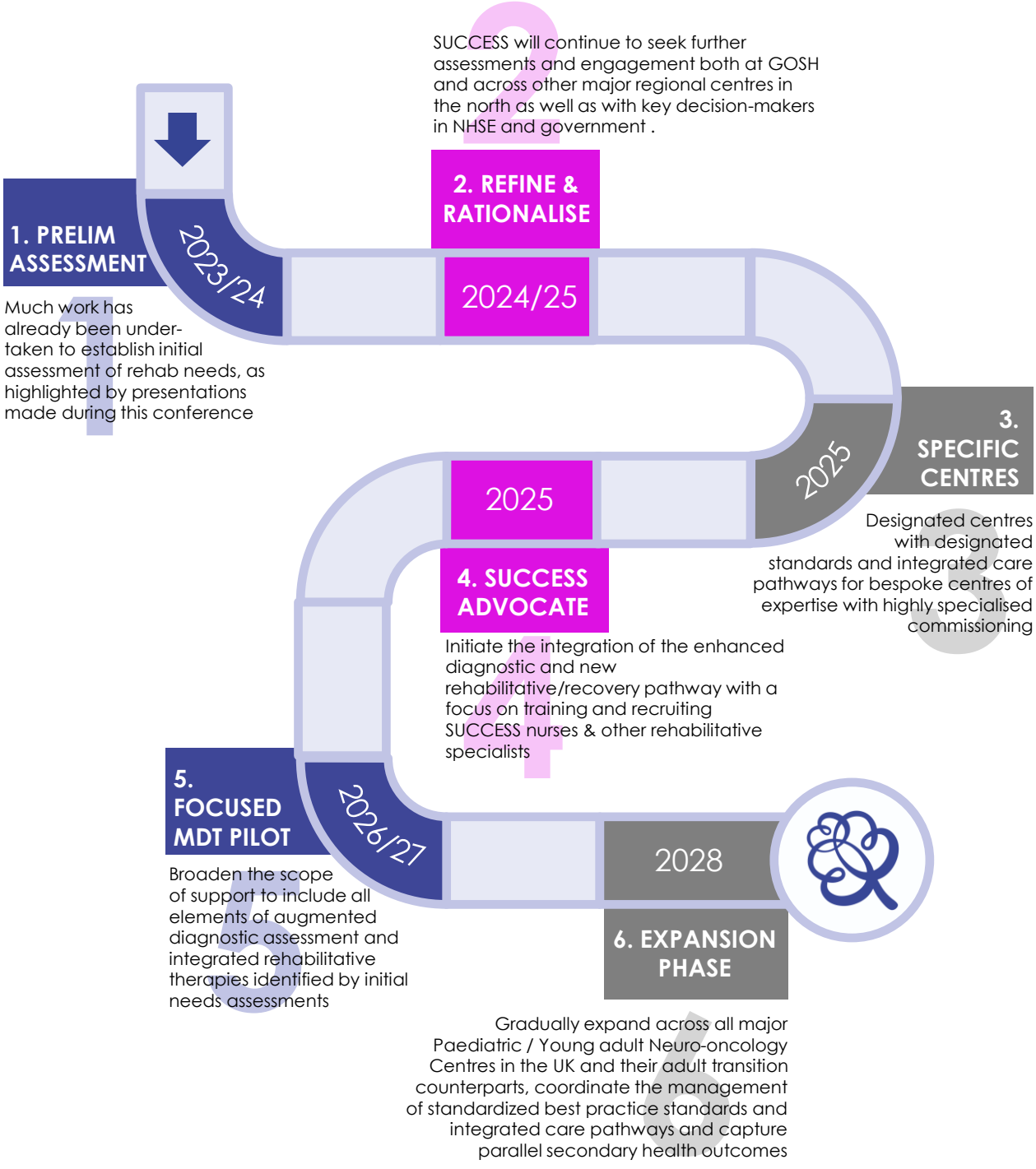
R Hon Derek Thomas MP

"We are rating "survival" as a "cancer win", but it's not a win for the child. We know what's needed for a better life, we know it's possible – now let's make it happen.

Our Strategy cont...

DELIVERING ACROSS 6 KEY MILESTONES

Our plan, over the next five years is to deliver on our vision, to create transformational change in the way health care is delivered to improve secondary health outcomes by delivering across **6** key milestones.



Our community

Watch:
The voices of survivors



Not just a conference

Our annual conference also serves to create a sense of community amongst our survivor population and the siblings and parents who attend.



We are all in this together

We all had time to enjoy Lunch, Visit our 'Destination' Lounge, ask questions of The Experts and Expert Survivors and indulge in some fun art therapy too!



"The charity was friendly and welcoming. I enjoyed being part of the community and catching up with other survivors.





"Seeing my son so happy to see his friends – other survivors - from the unfocused group was incredibly heart-warming. He loved being part of it – being part of his "tribe"



Our Thanks

We are immensely grateful to all our presenters who gave their time, expertise and passion. Survivors, parents, professionals and key parliamentarians alike provided inspiration, guidance support and hope.

THANK YOU to the friendly film crew Dale and Doug from Waring Stewart, our brilliant photographer Gary Manhine, art therapist Elwin Harewood and physiotherapist Daniel Bell

THANK YOU to Mr Harding, our parent employment lawyer from Dial Piper , our occupational therapists Pamela Anderson and educationalist Doug Stewart and survivors Matt Tozer and Tanya Bass for their workshop on accessing education and employment

THANK YOU to our new trustee, Dr Jane Williams a neurodevelopmentalist, for a fantastic educational needs symposium with other community specialists and debate with Derek Thomas

THANK YOU to the eminent medical and surgical specialists in pituitary tumours, Mr Simon Cudlip and Prof Marta Korbonits who explained the importance of such specialist care and to Drs Gan, Cerbone, Charlotte Malcolm, Mr Kristian Aquilina, and Profs Naomi Dale and Darren Hargrave, for their insight and understanding of how deep midbrain injury to the vital primitive hypothalamus affects all aspects of physiological and emotional well being and might be minimised and rehabilitated!

THANK YOU to the amazing eloquent Parliamentarians who continue to shape our parliamentary lobby (Lord Sandhurst, Derek Thomas MP), and to Dominic Grieve KC, our supportive and thoughtful patron.

THANK YOU to our energetic and tireless events organizer and Administrator extraordinaire Elaine Perkins, her SURVIVOR and parent volunteers and our new project lead Sam James ,who got us all there, kept us to time and kept us happy!

THANK YOU to the RSM for our new wonderful venue, fantastic audiovisual support, tasty catering and delivering our traditional celebratory SUCCESS cake and fizz with flair.

And finally… the BIGGEST THANK YOU to the survivors themselves and their families who contributed wholeheartedly to support and befriend their peers, inspire this annual exciting and special event between themselves and professionals towards change and whose voice we are proud to represent

Thank You!

Watch this space!

SUCCESS is not cure alone but the quality of that life during and beyond the cure process. Survivors need a **voice** – make sure you **come and join us** both in **Manchester** later this year, and help us raise funds as part of our Summer FUN-Draiser throughout the summer!

SUCCESS Roadshow

Manchester

Sat 19 October 2024
Holiday Inn

Help raise awareness this Autumn at the Success Roadshow in Manchester for Survivors of Childhood Brain Tumours and make sure to book your place.

More details will follow soon!

Summer FUN-Draiser

Nationwide

Throughout the summer
See QR code for current list of FUN-Draising events

Have some fun in aid of Success this summer and help us towards our £40,000 targets

SUCCESS CHARITY Life After Cure Ltd
100 New Bridge Road
London
EC4V 6JA

Registered number: 1188298
www.successcharity.org.uk

For enquiry – contact:
info@successcharity.org.uk

Why not help us and survivors by donating - every little helps!