



Brainbow

Working together to help children with brain tumours reach their full potential



2016 Annual Report

Sep 2015 - Aug 2016

Generously funded by:



Anna's Hope
For children and young people
with brain tumours



camille's appeal
supporting the recovery of children with brain tumours



TOM'S TRUST
caring for children
with brain tumours

IN THIS ANNUAL REPORT

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EXECUTIVE SUMMARY

Brainbow has reached a landmark and celebrated the end of its first three years providing rehabilitation to children with brain tumours in the East of England.

We are delighted that Anna's Hope, Camille's Appeal and Tom's Trust have committed to provide funding for a further two years (up to 31 March 2018). Without this support it would not be possible for the Brainbow service to continue, so we extend our special thanks and appreciation for this.

During the past year (2015/16) Brainbow has continued to develop the service provision and strategic thinking. The service has realised many achievements, some of which could never have been met without the support from our funding charities – Anna's Hope, Camille's Appeal, and Tom's Trust.

It is with sadness we have seen the closure of Camille's Appeal in August 2016. We would like to recognise the charity's invaluable contribution as a co-founder of Brainbow, and we thank the Founders, Martin and Hayley Shave, and their Trustees for their enthusiasm, passion and commitment. We are grateful that Camille's Appeal's remaining funds will be made available for the benefit of the paediatric brain tumour patients.

Brainbow has led to increased national and international awareness of rehabilitation for children with brain tumours and beyond. The service continues to be approached by others who would like to replicate the model elsewhere.

We would like to acknowledge the dedication and professionalism of all the staff who have worked for Brainbow together, helping children with brain tumours to reach their full potential.



Elisabeth Kerley
Project Coordinator



Dr Amos Burke
Clinical Lead



Amanda Cahn
*Associate Director of Operations,
Women's and Children's Services*



PURPOSE

This document gives an operational and strategic overview of Brainbow activity and performance during the year September 2015 to August 2016. The reporting year has been chosen over the last three years to coincide with the birth date of Brainbow. Hereafter the annual report will follow a standard financial year so the next report will be available in May 2017 to cover the financial year 2016/17.

BRAINBOW VISION

"To ensure all children with brain tumours reach their full potential"

ABOUT BRAINBOW

Brainbow's aim is to help children with brain tumours reach their full potential.

Brainbow provides coordinated specialist neuro-rehabilitation assessment and treatment for children and young people with brain tumours.

Brainbow is able to provide specialist rehabilitation support and continuity of care through the journey of children with brain tumours i.e. from their diagnosis, during their hospital admission, and beyond.



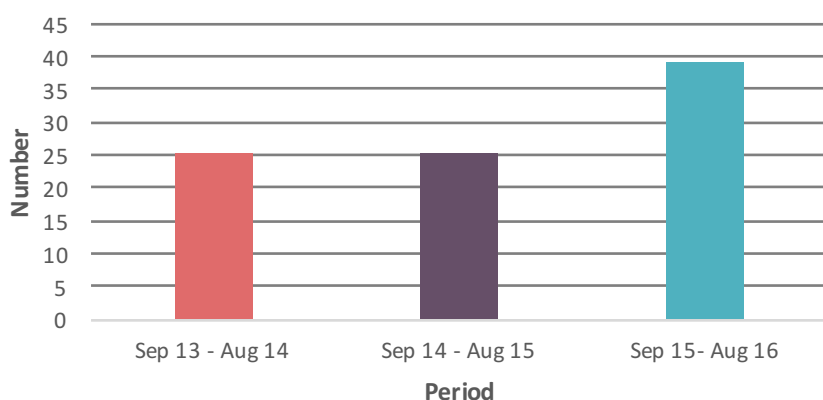
BRAINBOW STATISTICS

2015/16

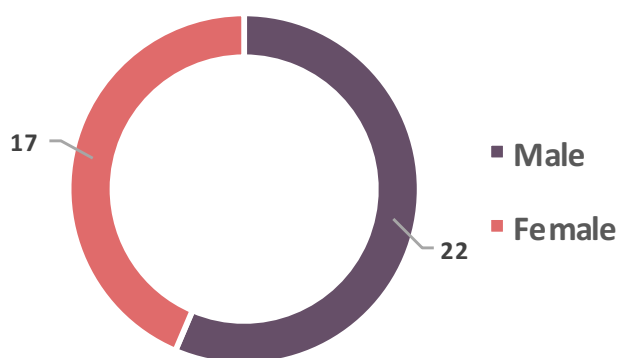
From September 2015 to August 2016, Brainbow cared for **122** children who had a brain tumour.

There were 39 newly diagnosed brain tumours between 1 September 2015 and 31 August 2016. This is a 56% increase from 2014/15. It is likely that this increase has been partly influenced by the **0.9%** increase in population per year in the East of England, which is one of the fastest growing areas in the country.

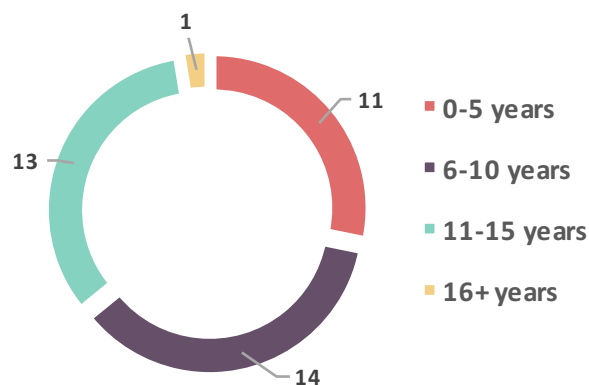
Newly diagnosed paediatric brain tumours seen by Brainbow



Gender split of newly diagnosed paediatric brain tumour patients seen by Brainbow 2015/16



Age groups of newly diagnosed paediatric brain tumour patients seen by Brainbow 2015/16



Continued...

BRAINBOW STATISTICS

2015/16

Number of contacts

During the period September 2015 to August 2016, the Brainbow team (excluding psychology) had 1305 inpatient and outpatient contacts. A *contact* is a recording on the Trust's patient information system (EPIC) regarding activity with or for a specific patient (covering face to face meetings and appointments, telephone calls, report writing). This system is still developing and expanding to allow us to capture even more data for the future.

The specialist clinical psychologist saw 55 patients between September 2015 to August 2016 and supported the assistant clinical psychologist in completing 21 neuro assessments in 2015.

Between May – August 2016, there were 74 outpatient appointments. The Brainbow approach involves multidisciplinary assessment and intervention so it is very common for children to be seen by two or more clinicians at the same time.

In keeping with all other departments in the hospital, the introduction of EPIC in October 2014 has led to significant change in the way that we record information. However the data that we had in the first year of Brainbow is indicative of what Brainbow has seen in the last three years. EPIC is being more fully utilised to enhance Brainbow's data collection.



"The Brainbow team is amazing, they are like my friends. They are so willing to listen and if my son isn't well enough to comply with their requests then they just do a little rehab, and then come back at another time. Not only do they provide the care to my son but they provide that emotional support to me too. It is amazing to have the support of Brainbow; only a little while ago there would never have been this support to children with brain tumours."

- Parent

BRAINBOW ACHIEVEMENTS

2015/16 Strategic successes include:

- ❖ An event was held on 30 September 2016 to share with key charities (who have an interest in fundraising for children with brain injury) a vision for a dedicated paediatric rehabilitation centre. The audience was unanimous that this project should move forward although no commitment to fundraising has been made at this stage. Although strictly outside this report period, the event was an activity of the reporting year which was planned during that time, although it was delivered afterwards.
- ❖ A re-submission of a bid for NHS funding was made in September 2016. This proposal includes paediatric brain tumour and acquired brain injury patients.
- ❖ Angela Kirby (Tom's Trust Specialist Clinical Psychologist) worked with a trainee (who was on placement) to produce a paper as part of their doctorate thesis; this was titled "Post traumatic Stress Symptoms in Young People with Cancer and their Siblings" and was published in August 2016. The research with siblings directly led to the development of the sibling distress thermometer which Kathy Cox (Tom's Trust Clinical Psychology Assistant) and Angela Kirby developed to help identify struggling siblings.
- ❖ Brainbow has received a few referrals from out-of-area Trusts and we are developing a business package to facilitate outside referrals as soon as possible.
- ❖ A successful Brainbow Away Day was held on 1 June 2016 to discuss strategy and objectives.
- ❖ The establishment of a *Brainbow Newsletter* which is circulated on a bi-monthly basis has been successful in promoting the work done with the rehabilitation of paediatric brain tumour patients, and how the charities have enabled this to happen. The newsletter has received very positive feedback.
- ❖ The Brainbow video was launched in March 2016 which is available on the Brainbow webpage and the charities' websites, and is good promotional material.
- ❖ Dr Amos Burke attended the CCLG (Children's Cancer and Leukaemia Group) Late Effects Group Education Day on 15 March 2016 to give a presentation on setting up a rehabilitation service for paediatric brain tumour patients, which was well received. The event was held in Newcastle and attended by over 80 delegates from across the UK.
- ❖ Katie Johnson (Anna's Hope Occupational Therapist) achieved a Sensory Integration Module 1; foundations and neuroscience. This was done through Ulster University.
- ❖ Antonia Kilcommons (Anna's Hope Speech and Language Therapist) is a joint author of a paper written with another Speech and Language Therapist from the Royal Marsden that has been accepted for publication by the American Speech-Language-Hearing Association Journal, titled "Dysphagia and long term feeding difficulties in the paediatric brain tumour population".
- ❖ Dr Amos Burke (Clinical Lead), Daniel Fountain (Medical Student), David Young (Anna's Hope Physiotherapist) and Katie Johnson (Anna's Hope Occupational Therapist) worked on a systematic review around daily living outcome measures used in neuro-rehabilitation for children with brain injury.
- ❖ Daniel Fountain, Medical Student (working with Brainbow under Dr Amos Burke's supervision) won the regional NHS Emerging Leader Award – submitted for his input into Brainbow. He was a finalist (Award Event 26/11/2015). Daniel is now a Foundation Doctor.

Continued...

BRAINBOW ACHIEVEMENTS

2015/16 Operational successes include:

- ❖ Kathy Cox (Tom's Trust Clinical Psychology Assistant) and Angela Kirby (Tom's Trust Specialist Clinical Psychologist) have developed individualised books for the brain tumour children about their diagnosis and coping with their condition. The team aims to evaluate these books going forward to see what impact this has for the patient.
- ❖ The therapists funded by Anna's Hope have created personalised 'All About Me' booklets for children being discharged with complex needs or whose ability has changed significantly. These are personalised with photographs of the children completing activities or sitting in their specialist seating or wheelchairs. The booklet aims to ensure that all people involved in that child's care know how best to complete moving and handling/use equipment/complete therapeutic activities or exercises. They include information about how the child likes each task to be completed. This is very much 'owned' by the child who can decide on the design.
- ❖ There is now a structured process for therapy students to apply for a placement within Brainbow to encourage a fair and open selection process, as well as providing interview experience for the students.
- ❖ The development of a formalised referral process to help triage and prioritise patients on our waiting list is in use.
- ❖ A consent form for case reports has been developed and is now live. This is for patients to give approval (if they wish) for their 'story' to be included in written and presentation materials. Every patient will be given the opportunity to complete a consent form at their introductory appointment. The aim is to streamline the process for us to present case studies in promotional materials and for the benefit of Anna's Hope and Tom's Trust.
- ❖ Camille's Appeal has provided funding for a new Administrative Assistant post for which we are extremely grateful. This post has made a significant difference to the team, relieving them from admin duties and enabling processes to be more streamlined.
- ❖ Tom's Trust has provided funding for a Clinical Psychology Assistant which has had a major impact on our ability to provide neuropsychology testing for children with brain tumours, and has now become a fundamental part of the Brainbow service, with continued funding support from Tom's Trust.
- ❖ There has been the establishment of a neuro-rehab multidisciplinary team (MDT) meeting held twice-monthly to discuss patient rehabilitation needs and goals.
- ❖ There continues to be a useful monthly team meeting which works well.
- ❖ The Brainbow service has purchased a shed as space is tight. This is for staff to store larger equipment items for the paediatric brain tumour patients.
- ❖ The therapists funded by Anna's Hope have developed a closer working relationship with the Music Therapy team on the wards. Joint goals and sessions have been established to provide music therapy to the paediatric brain tumour patients, and this has helped with integrating therapy into every day activities that are motivating and fun for the child.

"Everyone has been helpful and kind, and it has been really good that I haven't been rushed to answer questions."

- 15 year old patient

"Brainbow has really supported Mum and they have spent time with us and answered all our questions. We have been really reassured going home and they have a supportive network."

- Dad of above patient

BRAINBOW IMPACT

Brainbow has had a positive impact on the paediatric wards at Cambridge University Hospitals. Ward C2 reports that "it is a fantastic resource to have a dedicated team that can focus specifically on children with brain tumours and the huge impact this has on many aspects of everyday life that we all take for granted, and that in some cases, this can be lifelong.

"Families have clear contact and the fact that the team meets them from day one (from being in an acute bed on either ward C2, C3, D2 or PICU) means that relationships can be developed right from the outset.

"Brainbow has also enabled us to have more resources available for these children, and it can improve the transition home or even aid access to The Children's Trust, Tadworth (a nationally commissioned specialist neuro-rehabilitation service for children with brain injury) if needed."



RESEARCH AMBITIONS

Brainbow has only been in existence for three years but in this short space of time the service has stimulated renewed interest and discussion on the subject of neuro-rehabilitation for children with brain tumours across the UK. Rehabilitation services for children in the UK are unfortunately quite underdeveloped and there is a need for high quality evidence to guide the direction of service development for the future. The Brainbow service has been active in contributing to scientific journals, conferences and specialist meetings.

There have been significant developments on the Addenbrooke's campus with regard to cancer and children's services, and these have allowed us to consider more rigorous research questions regarding rehabilitation. As part of a comprehensive programme to address the needs of a group of children with low grade brain tumours, proposals are in development to study:

1. The impact of differing models of rehabilitation service provision (including Brainbow)
2. The application of functional neuro-imaging (the use of techniques such as MRI to show not only anatomy but function of different parts of the brain) to investigate the effect of therapy interventions on brain function

This is a very formative time in the development of wider understanding of rehabilitation, and the Brainbow service is positioned to take a leading role in aspects of this field.

OUR FUNDING CHARITIES



"There are few opportunities as a professional to work as part of a close therapeutic team providing rehabilitation to children in hospital and as well as when they have gone home. It is a pleasure to be part of Brainbow and to feel like you are making a real difference."

- Lizzie Berry, Advanced Specialist Speech and Language Therapist

Funded by Anna's Hope

"Anna's Hope is proud to fund all the physiotherapy, occupational health and speech and language therapy as part of the Brainbow Service. We could not do this without the generous donations and amazing fundraising efforts from all those who support our charity. Every penny they have raised goes towards helping children with brain tumours reach their full potential. Thank you."

- Carole and Rob Hughes

Anna's Mummy and Daddy and Founders of Anna's Hope



"It is a great privilege to work with such a dedicated team, whilst providing the operational support needed to deliver the Brainbow service. The patients come first in everything."

- Elisabeth Kerley, Project Coordinator

Funded by Camille's Appeal

"Brainbow has transformed the life of children and families in the East of England. Brainbow has become the byword for rehabilitation for children with brain tumours, and the establishment of this service just shows what can be done by sharing a vision. We want to acknowledge Camille's Appeal's invaluable partnership with Brainbow, and without everyone we would not be who we are and what we are."

- Dr Amos Burke, Clinical Lead



"We are so grateful that Tom's Trust has agreed to fund the psychology time for the Brainbow team. It is wonderful to be working as part of a very inspiring and committed MDT that is dedicated to children with brain tumours from the time of diagnosis."

- Angela Kirby, Specialist Clinical Psychologist

Funded by Tom's Trust

Tom's Trust is passionate about providing clinical psychologists for children with brain tumours. It is an underfunded and under valued but critical part of supporting the child and their family from the point of diagnosis. Our work cannot be done without the incredible generosity of our supporters. We are so proud and honoured to receive that support, which allows us the platform to change this group of children's lives."

- Deborah Whiteley

Tom's Trust





"Brainbow has been a massive support at a difficult time for all the family. Physio has been invaluable; they have come every day forming relationships. We're not sure where we would be without them"

CASE STUDY

PAUL

(Pseudonym)

- ✦ Paul is 15 years old. He was diagnosed with a brain tumour when he was 12 years old after a short time of feeling unsteady on his feet, headaches and feeling sick.
- ✦ Paul had surgery to remove the tumour and after the operation he spent many weeks in the hospital as he developed a condition where he wasn't able to control his muscles or speak.
- ✦ Paul needed to have further treatment including radiotherapy and chemotherapy.

- ✦ Paul was met by the team when he first came into the hospital after being diagnosed. This was very useful for knowing how he was before the operation and for both him and his family to get to know the team.
- ✦ After the operation, Paul had intensive input by the Occupational Therapist and Physiotherapist for learning how to control his head, sit up, start to use his hands and eventually to stand and walk again. This took a long time and Paul had to work very hard to achieve his goals. Paul also needed equipment for being able to participate in activities safely when he went home.
- ✦ Paul was also seen by the Brainbow Speech and Language Therapist to support his eating and drinking and help with his communication.
- ✦ Paul's family were seen by the clinical Psychologist as an inpatient to support them during this distressing time.
- ✦ Meetings were organised to plan for when Paul went home. School also attended and it was decided that initially home tutoring would help with Paul gradually returning to school when he was ready.

- ✦ Paul was referred to local therapy teams but also came back in to see the Occupational Therapist and Physiotherapist for further input whilst he was having his treatment. This helped 'bridge the gap' before community teams were able to see him as it was so crucial for Paul to continue with his rehabilitation.
- ✦ There were further meetings held with school to help Paul participate as fully and safely as possible when he returned and to give advice to staff.
- ✦ Two years after his brain tumour diagnosis (and a year after treatment finished), Paul was referred to be seen for full, specialist multi-disciplinary assessment with the Brainbow Service. It was hugely beneficial that all professionals knew Paul's journey from the point of diagnosis and how he had been prior to treatment. This enabled much better quality of assessment and understanding of his strengths and needs.
- ✦ After the assessment, Paul completed work with the Clinical Psychologist and also saw the Occupational Therapist for work on his independence skills. Paul also saw the Physiotherapist for a session looking at his mobility outdoors as this was one of the factors stopping him going out with his friends.

- ✦ Paul is now at school and completing GCSEs. Brainbow has worked with Paul, his family and school to work out which courses would be best, and he is enjoying computing in particular!
- ✦ Paul is slowly growing in confidence to go out with his friends and has even been to the local shop by himself to buy a magazine.
- ✦ Paul and his family continue to see the Clinical Psychologist alongside the oncology service Counsellor. Paul was discharged from community therapy services after the initial period after discharge from hospital so the Occupational Therapist, Speech and Language Therapist and Physiotherapist also see Paul when there is a specific goal.

CASE STUDY

LISA

(Pseudonym)

- ✦ Lisa is 9 years old. She was diagnosed with a brain tumour in early 2015 when she was 7. Before she was diagnosed, Lisa had found walking, using her hands and balance difficult. She had also experienced frequent headaches and sickness.
- ✦ After her operation, Lisa had 6 weeks of radiotherapy and then chemotherapy.
- ✦ As a result of the side effects of her treatment Lisa struggled to eat enough. She therefore had some surgery to insert a feeding tube to support getting enough energy.
- ✦ Lisa had many worries and anxieties following her diagnosis and throughout her treatment. This could manifest as anger.
- ✦ Her parents struggled, at times, to cope with her behaviour.

- ✦ Lisa was met by the Speech and Language Therapist, Occupational Therapist, Physiotherapist and Psychologist when she first came to the hospital, before her operation.
- ✦ After her surgery, Lisa did well and went home quickly with Occupational Therapy and Physiotherapy support.
- ✦ Lisa was followed up by Occupational Therapy and Physio as an outpatient to assess and give advice about her balance and use of her hands. They also spoke to school and gave advice around how best to support Lisa's participation in school activities such as Physical Education and activities in the classroom.
- ✦ Lisa was seen throughout her treatment by the Psychologist to help her manage her anxiety and angry feelings.
- ✦ Lisa's parents were also seen by the Psychologist to help them understand and manage her anger.

- ✦ The Psychologist undertook a cognitive assessment as there were concerns about Lisa's cognitive functioning. The assessment identified areas of need and an Education Health Care Plan was put in place to provide the necessary support Lisa needed in school.

- ✦ Later on, Lisa had difficulties with some aspects of personal care and so was seen by the Occupational Therapist to help her to become more independent.
- ✦ There were also concerns around sensory processing because Lisa had difficulties with concentration, fidgeting, bumping into things and hyperactivity. The Occupational Therapist looked at how Lisa was able to understand where her body was in space, and how this affected her participation in activities at school and home.
- ✦ Lisa had on-going issues around her feeds so these were explored by the Psychologist.

CASE STUDY

JOSHUA

- ✦ Joshua is a young man who loves Lego. He was diagnosed with a brain tumour in August 2015 when he was 7 years old.
- ✦ Joshua had 8 hours of surgery and then started with 3 rounds of chemotherapy. He then had to have radiotherapy each day for 6 weeks. During this time Joshua stayed at Addenbrooke's with his Mum or Dad.
- ✦ After this, Joshua had another 3 rounds of chemotherapy, he was able to receive this at the Norfolk & Norwich Hospital nearer to home.

- ✦ Joshua was seen by the Brainbow Occupational Therapist, Physiotherapist, Speech and Language Therapist and Clinical Psychologist at various times. They all learnt a lot about Lego!

- ✦ Joshua loved going to school when in the hospital, and he was able to go to school when he was at home as well.
- ✦ Joshua's school were really generous and raised money for the Brainbow Service; £350 from their Christmas concerts.

- ✦ It was a very exciting day in May this year when Joshua was able to ring the end of treatment bell!
- ✦ Congratulations to Joshua and his family!

- ✦ Throughout his treatment, Joshua was always able to raise a smile from everyone who met him and his determination was wonderful to see.
- ✦ He taught his team in radiotherapy about Lego Ninjago, and tested them regularly.



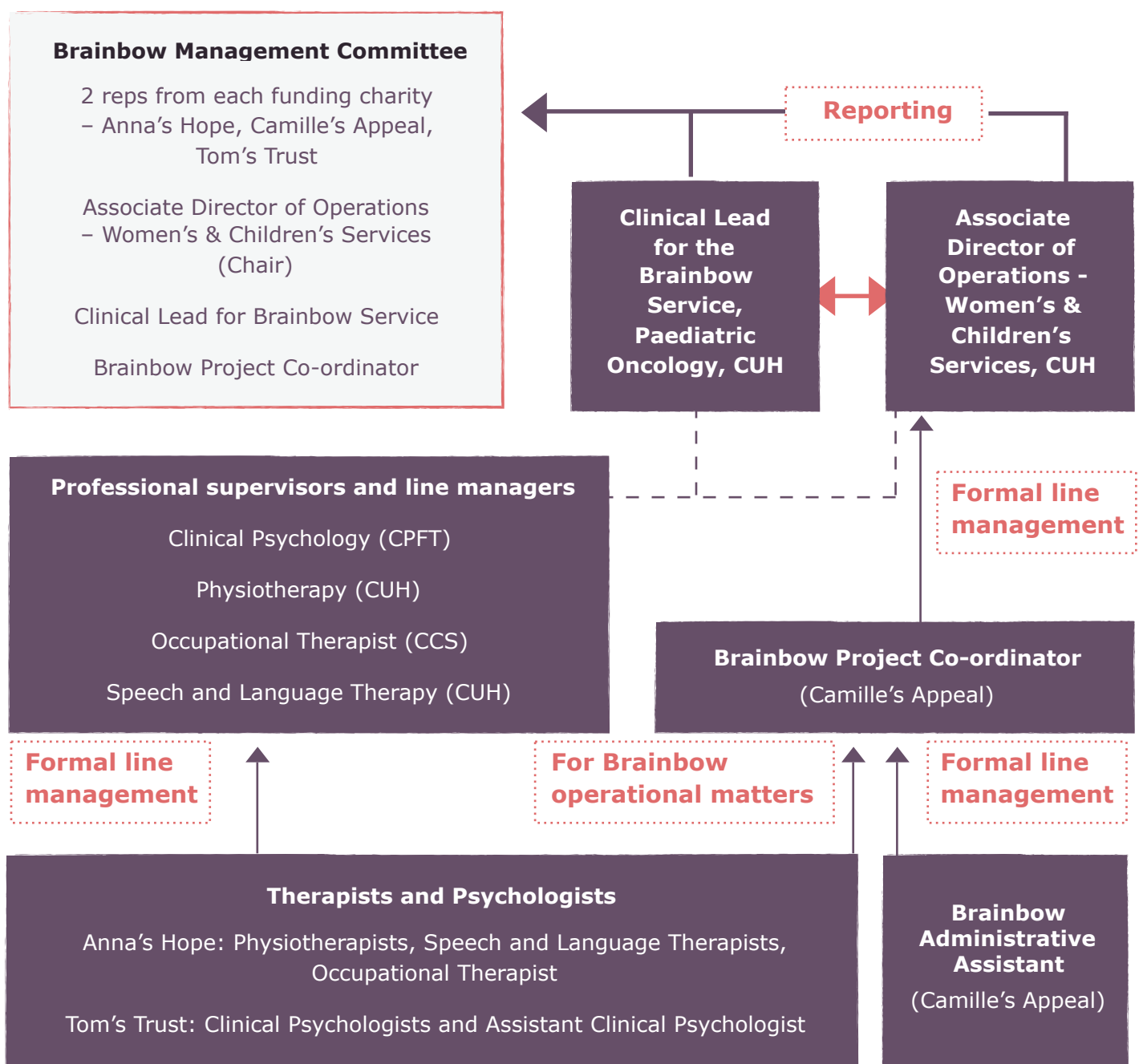
BRAINBOW ORGANISATIONAL AND GOVERNING STRUCTURE

Brainbow Management Committee

The Brainbow Management Committee meets on a quarterly basis. Between September 2015 and August 2016, the Committee met on:

❖ 18 November 2015, 16 March 2016, 15 June 2016

The Annual General meeting took place on 18 November 2015.



CHARITABLE FUNDING

The charities **Anna's Hope**, **Camille's Appeal**, and **Tom's Trust** have provided funding during the past three years (September 2013 to August 2016), as detailed below. The Brainbow service is indebted to the charities for this considerable contribution which has ultimately resulted in significantly improved outcomes for children with brain tumours.

Funding from Anna's Hope

Funding
£575,448



Anna's Hope
For children and young people
with brain tumours

Funding from Camille's Appeal

Funding
£118,451



Funding from Tom's Trust

Funding
£187,945



**The total funding for
Brainbow over the past
three years amounts to:**

Total
£881,841

We are delighted that continued funding has been provided by all three charities until 31 March 2018

BRAINBOW STAFFING

There have been a number of staffing changes over the last year:

Physiotherapy

There has been a lot of change in the physiotherapy department over the past year. We are pleased to announce the safe arrival of a baby girl of one of the Physiotherapists. A second Physiotherapist has been successful with an application for a Masters in Research so is on secondment. The Physiotherapy role is currently being covered.



Anna's Hope
For children and young people
with brain tumours

Management and Administrative Support

We welcomed a new Project Coordinator who started in February 2016 replacing the previous post-holder who has moved on to another role. We are delighted that Camille's Appeal has provided further funding for an Administrative Assistant. The role provides full admin support to the whole team which has been a huge asset and has enabled the team to have more patient focused time.



Psychology

We were delighted to welcome a new Clinical Psychologist in October 2015. We said farewell to our first Assistant Psychologist in August 2016 and wish them well in their future career. Psychology input for children has continued through these changes.











Voluntary Support

We have been grateful to have interest from one of our Cambridge University student doctors, Daniel Fountain who, working under supervision of Dr Amos Burke, has assisted the team with various publications.

Continued...

BRAINBOW STAFFING

The following posts are currently funded:

Post	Banding	WTE	Funded by
Physiotherapist	Band 7	1.0 (37.5 hours per week) (2 x 0.5 WTE posts)	Anna's Hope  Anna's Hope For children and young people with brain tumours
Speech and Language Therapist	Band 7	1.0 (37.5 hours per week) (2 x 0.5 WTE posts)	Anna's Hope  Anna's Hope For children and young people with brain tumours
Occupational Therapist	Band 7	1.0 (37.5 hours per week)	Anna's Hope  Anna's Hope For children and young people with brain tumours
Project Co-ordinator	Band 7	0.4 (15 hours per week)	Camille's Appeal  camille's appeal supporting the recovery of children with brain tumours
Administrative Assistant	Band 3	0.67 (25 hours per week)	Camille's Appeal  camille's appeal supporting the recovery of children with brain tumours
Specialist Clinical Psychologist	Band 8b	0.2 (7.5 hours per week)	Tom's Trust  TOM'S TRUST caring for children with brain tumours
Clinical Psychologist	Band 8a	0.6 (22.5 hours per week)	Tom's Trust  TOM'S TRUST caring for children with brain tumours
Assistant Psychologist	Band 5	1.0 (37.5 hours per week) (Vacancy)	Tom's Trust  TOM'S TRUST caring for children with brain tumours

ADDITIONAL INCOME AND EXPENDITURE

Paediatric Neuro-oncology Rehabilitation Fund

The paediatric neuro-oncology rehabilitation fund is a standalone fund held by the Addenbrooke's Charitable Trust (ACT) which was set up several years before the development of Brainbow. The fund is made up of donations from the public and we are very fortunate that this additional funding is accessible to the Brainbow service.

The balance on 1 September 2015 was £49,324.67 and on 31 August 2016 was £50,504.51.

Between 1 September 2015 and 31 August 2016 the total income and expenditure was as follows:

Total Income	Total Expenditure
£26,776.68	£26,296.45

At the Brainbow Management Committee meeting on 16 March 2016 it was agreed that the balance in the Paediatric Neuro-oncology Rehabilitation Fund of £50,000 would be spent, and thereafter the account would not be managed by the Committee but would revert to the Trust's standard arrangement. To date the expenditure from that balance totals £5,927.06.

Fundraising

Brainbow has undertaken no active fundraising however it has clearly captured the imagination of many supporters and we are very grateful for the unsolicited funds that have flowed in our direction. In response to this overwhelming support to Brainbow we have decided to scope a 'Friends of Brainbow'.

We are very grateful to the three funding charities which have provided additional funding throughout the year to help us meet the service needs.

The Trustees of Camille's Appeal have provided ongoing funding for the Project Coordinator and Administrative Assistant posts despite the closure of the charity in August 2016. They will also be transferring their remaining funds to a dedicated charity account with Addenbrooke's Charitable Trust (ACT), and this will be made accessible to the Brainbow service only and will be spent on particular projects selected by Camille's Appeal.

We would also extend our thanks to a number of smaller charities, groups and individuals who have donated to the Paediatric Neuro-oncology Rehabilitation Fund. In August 2016, the *Joshua Tarrant Memorial Fund* raised £11,473.25 for the benefit of paediatric brain tumour patients, so this has funded an interactive play mat for one of the ward areas.

"My brother and his friend did a sponsored 100mile bike ride through the night in respect of our son who was diagnosed with a brain tumour in November 2015. We as a family hope that the amazing amount of money that was raised will help other families and children recover fully. Brainbow helped us as parents and our son to recover after successful surgery at Addenbrooke's, and we will be forever grateful to the Brainbow team alongside all other medical staff within Addenbrooke's. We have raised an amazing amount of £2900 to thank you for our son's care."

- Parent

EVENTS OF THE PAST YEAR

Thank you to Camille's Appeal

In June 2016, members of the Brainbow Management Committee presented the trustees of Camille's Appeal with a token of recognition for the invaluable contribution as a co-founder of Brainbow as the charity prepared to close in the summer.

Alongside Anna's Hope and Tom's Trust, Camille's Appeal founded Brainbow in 2013 working with CUH to provide a rehabilitation service in the East of England for children with brain tumours.

The presentation took place at the Brainbow Management Committee Meeting on Wednesday 15 June 2016.

The presentation ended with the cutting of the Brainbow Cake.



A vision for Paediatric Neuro-Rehabilitation

Cambridge University Hospitals (CUH) held an important event on Friday 30th September 2016 to share a vision for a paediatric neuro-rehabilitation centre for the East of England. A number of charities (who have previously been interested in fundraising for children with brain injury) were invited to attend the event to see if they would like to help us deliver this vision through fundraising mechanisms.

A paediatric neuro-rehabilitation centre will be a key part of our ambitious plans for delivering world-class children's care, here on the Addenbrooke's campus, serving the region and beyond.

Brainbow was used as an exemplar to demonstrate how charities working together can deliver a vision.

The event was opened by Professor Richard Gilbertson, Director of Cancer Research UK who has a specialist interest in paediatric brain cancer.



BRAINBOW SERVICE STRATEGY

In 2013, the Brainbow service set some objectives to be achieved by the end of the initial three years. Progress has been made on each objective over the past three years, as demonstrated below.

Objective	Progress to date
To develop a specialist core team at Addenbrooke's who can provide neuro-rehabilitation assessment and some therapy for children with brain tumours living in the East of England. The core team will include Occupational Therapist, Physiotherapist and Speech and Language Therapist funded by Anna's Hope, and a Clinical Psychologist funded by Tom's Trust	This core team has now been well established. In addition to the funding for a Clinical Psychologist post, Tom's Trust has also provided funding for a Clinical Psychology Assistant which is now a fundamental part of the Brainbow service. The multi-disciplinary team works very closely together to provide neuro-rehabilitation assessments and therapy for children with brain tumours.
To ensure that all children with brain tumours in the East of England receive a clear programme of rehabilitation intervention based on standardised needs assessment	The patient's treatment plan is discussed and agreed at the neuro-oncology multi-disciplinary team (MDT) meeting. Each patient seen by Brainbow has an introductory assessment followed by a 6-week therapy block as part of the standard care.
To demonstrate and report on improved outcomes for children with brain tumours as a result of coordinated rehabilitation assessment and therapy	Functional measures are ongoing and this will take several years to achieve.
To gain a better understanding of how children treated for brain tumours can reach their maximum potential following treatment and to maximise opportunities to share this learning	Brainbow has been frequently requested to showcase the model and learning outcomes at regional and national events. Learning is shared with colleagues both within the hospital and at external events.
To embrace new ways of working including joint therapy sessions	Joint therapy sessions held with the patients enabling collaborative provision of care and treatment is now embedded in the Brainbow service.
To improve the experience for families in terms of better coordination of rehabilitation services	An improved experience in the coordination of rehabilitation services has been realised by over 200 patients and their families who have been seen by the Brainbow service.
For the Brainbow service team to work collaboratively with families, charities, and existing teams within CUH and across the East of England to improve rehabilitation therapy provision	Brainbow works collaboratively with a wide range of teams within CUH, the community, Tadworth, families, and charities to improve rehabilitation therapy provision. We have worked closely with Anna's Hope, Camille's Appeal, and Tom's Trust who have increased their funding to allow for improved provision. The Brainbow team collaborates with the Adam Rogers Trust's therapy team at CUH.
To develop a service that will be sustainable in the East of England after the three-year charitable funding period	Funding has been agreed by Anna's Hope, Camille's Appeal and Tom's Trust for a further two years until 31 March 2018. Operationally the service is sustainable but only with external funding. A bid was submitted to commissioning in September 2016 for NHS England funding and the outcome is awaited.

Continued...

BRAINBOW SERVICE STRATEGY

Objective	Progress to date
To develop a sustainable model of care – an optimal rehabilitation package – which can be rolled out across the East of England, and beyond	The Brainbow model of care is well established. There has been increased national and international awareness of Brainbow, and the service continues to be approached by others who are interested in replicating the model elsewhere. We are looking at developing a package of care for patients who are not from the East of England.
To develop a system to record the rehabilitation needs and treatment results of all children with brain tumours across the East of England	A new patient information system (EPIC) was introduced at CUH in October 2014. This has brought significant change to the way we record data. EPIC is being more fully utilised to enhance Brainbow's data collection.
To meet and hopefully exceed the expectations of Anna's Hope, Camille's Appeal and Tom's Trust	We have sought to provide regular information and updates such as the newsletter, reports, learning events, and website. We have accepted the very generous continued support and funding of Anna's Hope, Camille's Appeal and Tom's Trust as evidence that we are meeting this objective.

"Our liaison with Brainbow gives us a greater insight and understanding of each individual's specific diagnosis, their particular needs and psychosocial information. This in turn means that we are able to deliver an individualised learning plan, to aid recovery and rehabilitation, enabling a more successful return to home and school. These links with the Brainbow team have become essential and invaluable, helping to improve the service we can provide, for a better outcome for the pupil in terms of their education."

- Sally, Nadia, Katie, Alex - Hospital School Teaching Team

LOOKING AHEAD

2017/18 AND BEYOND

Family Focus

- ❖ Working with families to improve care for all children with brain tumours across the East of England. To achieve this there will be a focus on obtaining formal feedback from which will act to improve the core pathway. Feedback from families will be incorporated into the Brainbow reports.
- ❖ To continue to develop the Brainbow newsletter to ensure all the team working with children are aware of what the Brainbow teams are doing and ensuring that we have a good number of patient stories and feedback.
- ❖ To promote joint working and fully develop the MDT approach and work towards naming a lead therapist for each child.
- ❖ Improved support to those children who in the past have had a brain tumour and are either transitioning into secondary school or adult service, recognising what a challenging time this is for the child and family.

Sustainable Model of Care

- ❖ Continue to work with NHS England highlighting the need for the service to be fully commissioned. This will be via similar events to that of 30 September 2016, collating family feedback and collecting outcome measures highlighting the successes of the Brainbow Team.
- ❖ To scope what the model of care would look like for children with brain tumours from an external referral.
- ❖ To continue to work up the capital case of need for a rehab facility so that we are able to fully maximise every child's potential.

Our Staff

- ❖ To ensure that the Brainbow Team continues to develop professionally.
- ❖ To improve our retention of high quality and committed teams, recognising that there will always be some turnover of staff.
- ❖ To continue to develop the monthly team meeting so challenges and opportunities can be shared and action taken.
- ❖ To identify a funding stream going forward past 2018 if funding is not secured via the NHS England commissioning route.

Continued...

LOOKING AHEAD

2017/18 AND BEYOND

Sharing what we have learnt

- ❖ To continue to publish in journals, present posters or presentations.
- ❖ To host another learning event in 2017/18 based on the success of previous events.
- ❖ Actively encourage other providers to visit and observe the Brainbow model of care, all children with brain tumours deserve the same care and expertise.
- ❖ To work with the internal communications team to update and refresh the Brainbow website, which is an external facing website for families to access as well as other healthcare professionals.

Fundraising Opportunities

- ❖ To take all opportunities to work with families who want to fundraise to continue to help deliver care to children with brain tumours.
- ❖ Develop an ongoing/expanding wish list (to include the rehab facility) so we have continuous supplies to give to both large and small donors.
- ❖ To be responsive when requests come to the service to ask for representation at events/schools for fundraising activities – making full reference to how Brainbow was established and the ongoing funding from Anna's Hope and Tom's Trust.

As the NHS faces continued financial challenges we need to work with all our partners to ensure that children with brain tumours continue to get the acute care but recognising the vital importance that rehab will make – ensuring every child has the opportunity to reach their full potential. Working together we know that this can be achieved, and will take every opportunity to promote the importance of providing the outstanding care children with brain tumours receive from the Brainbow Team.

“Thank you so much, you and your team
have been exceptional.”





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