



Romeo's Story

Before Romeo was born his parents knew that Romeo had a heart condition, however they anticipated a couple of surgeries, and all would be well... however this was not to be.

Romeo was born in 2019 and had his first open heart surgery aged 4 months. When Romeo was a year old, he was referred to a Paediatric consultant and admitted to a specialist hospital as he was just not well.

Romeo was reviewed and taken to the Cath Lab to check the pressures in his heart, where he arrested. He went to recovery and arrested again in his mum's arms before being transferred to Paediatric Intensive Care Unit (PICU).

Mum shared that she was told, on her own, on the ward round by the consultant that day (not the consultant they knew) that Romeo had cardiomyopathy and needed a transplant. Mum was left to tell her husband. Mum wasn't sure if she remembered everything, wasn't even sure whether she had heard correctly.

This was all during the start of Covid, so for the majority of the time mum was left alone waiting for news.

Mum was advised that Romeo had complete heart block and needed a pacemaker. Due to Covid regulations, only mum could be with Romeo, so dad was not able to see his son. As no one really knew what could happen with Covid, the family just wanted to take Romeo home as soon as he was stable enough as they did not feel safe.

Please be aware, you may find this story distressing.

Romeo's story is a reflection of what occurred from mum's perspective and is being shared with the intent to improve the lives of children and young adults, their loved ones, families, carers, and support those working in Palliative and End of Life Care, as to what was and continues to be important to Romeo and his family.



Once home, they brought Romeo in for appointments every one to two months to see the cardiologists. The possibility of a heart transplant was discussed; however it was explained this may be difficult due to Romeo's size and the fact they did not have any genetic results despite multiple testing. The specialist hospital therefore felt Romeo was not a candidate for transplant.

As a family, they needed to know whether Romeo could have a transplant or what else may be possible, so at 15 months old, the family went for a private second opinion. The outcome confirmed Romeo had severe restrictive cardiomyopathy and the outcome was shared with the specialist hospital.

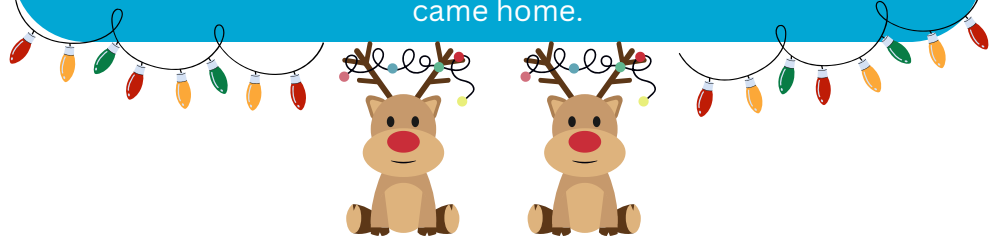
Romeo was then referred to the transplant team for review. They shared the same views that until they knew Romeo's genetic condition, they would not be able to list for transplant. The transplant team added that they also wanted a skin biopsy to try to establish a genetic baseline; to date the family still do not know the reason for Romeo's conditions. During this time Mum had requested to be put in touch with palliative care due to the severity of Romeo's diagnosis however mum shared that this request was not actioned.

Romeo and his family had other complications to contend with; Romeo was awaiting a stoma reversal and insertion of a percutaneous endoscopic gastrostomy (PEG*) tube due to issues with feeding and sickness. However, any surgical intervention was high risk.



Two weeks before Christmas 2020, Romeo was just not himself. This progressed, resulting in an ambulance being called and being taken to a local hospital. Mum knew what was wrong, Romeo had had a stroke. The transplant team had advised that Romeo was a high risk of having a stroke and should be on aspirin. Mum advised she had been chasing the consultant for aspirin, however had received no response.

On arrival at hospital resus Romeo was taken straight to the children's day unit as he was known there. Mum shared, no one came to see Romeo for two hours, when mum followed this up, she was told Romeo was admitted with a suspected broken arm. Mum explained the situation however felt she had not been listened too. Scans confirmed Romeo had indeed had a stroke. Mum wrote a complaint, as she needed to highlight that not having aspirin could have led to this occurring. Romeo recovered from his stroke and came home.



At the beginning of January 2021, Mum took Romeo to the specialist hospital due to effects from severe heart failure. It was decided Romeo would be started on an intravenous (IV) medication for his heart failure and they would do his operation, this was the beginning of their 110 days admission in PICU. Romeo was so poorly; he was intubated, extubated, transferred to ward, saturations dropped, (which was not like Romeo), became septic and went back to PICU. He had his skin biopsy, stoma reversal, operation on his testicle and a PEG and there were so many times the family thought they would lose Romeo.

Whilst Romeo was on PICU, the family met the paediatric palliative care consultant for the first time, even though they shared they had previously asked to speak with someone from the team.

During discharge from PICU and Advance Care Plan (ACP**) discussions - which was started in May, once Romeo's care was deemed palliative - the pacemaker consultant suggested including a decision to turn Romeo's pacemaker off. Mum was not ready for this at this time and they compromised and altered the rate from 90bpm to 50bpm.

Romeo was deteriorating, he had gone into kidney failure and the family were supported to get Romeo baptised. Although each time Romeo deteriorated, the family thought 'this was it' Romeo pulled through, time and time again. The palliative care team kept checking in with the family.

So much variation, lots of talking about what ifs and what were the families wishes and for the first time... aspirations, what would the family like to do?

The paediatric palliative care consultant came and made Romeo more comfortable, as he seemed in pain.

The consultant tried another transplant team, however after more tests and months of discussion they were advised that the second transplant team could not list Romeo for transplant either.

* - is a feeding tube which passes through the abdominal wall into the stomach so that feed, water and medication can be given without swallowing.



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When the consultant spoke about palliative care, the family shared that they just thought – think die, doom and gloom. However, the conversation was focussed on what was important to Romeo and the family, what the family wanted for Romeo, and for them as a family. What was the family's aspirations? So the family visited Peppa Pig World – an amazing day that the whole family will remember. This was made possible by the fantastic planning by the PICU team and arranging of free early access to Peppa Pig World, which included a meet and greet, supported by the PICU ambulance service.



*Child and Young Person's Advance Care Plans, also referred to as ACPs, have been standardised across the country and a blank one can be found on: <http://cypacp.uk/>



The paediatric palliative care consultant then supported the family to talk about next steps, the family wanted to take Romeo home. The paediatric palliative care team worked with colleagues to wean Romeo off the IV drug that could not be given in the community. The suggestion was to go to the children's hospice first then home, so the family could be supported.

Romeo moved to the hospice, however due to Covid restrictions they had to go to the older part of the hospice. This didn't work for the family as it was too isolating, so they preferred to go home.

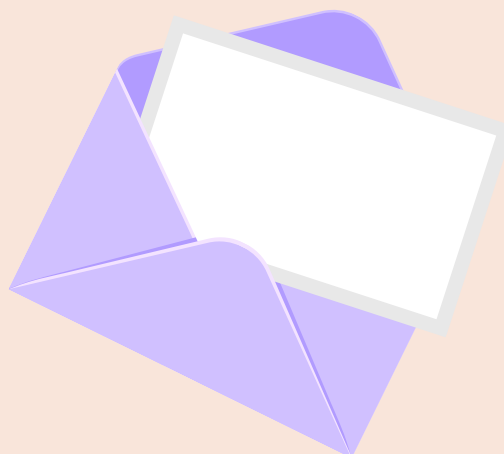


At home the family got into their own routine, with the support of an amazing community children nurse who visited weekly initially. The intensity of visits increased as Romeo's condition altered. The paediatric palliative care consultant linked in with community children nurse and the family to review, which the family felt reassured by.

As Romeo's condition deteriorated significantly, a continuing healthcare package was agreed, initially 2 nights a week, however this soon increased as Romeo's needs did. As mum was heavily pregnant a plan was agreed for Romeo for when mum had her baby. However, baby came 3 weeks early, so Romeo had to go to the children's hospice urgently so he could be cared for 24/7.

During September 2021 Romeo was sleeping 20 hours a day. By October 2021 Romeo was being sick a lot, so the paediatric palliative care consultant helped with medication to ease this.

Romeo's ACP was being followed and the family were aware Romeo was deteriorating further.



The lead paediatric palliative care consultant gave mum an envelope, which mum was advised she could read if she wished too, however she could also just put in a draw for when the time came that Romeo died. It had the instructions of what to do. Mum didn't feel the need to read it, however really valued knowing it was there for when the time came.



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On 12th October 2021 at 2am, the night nurse knocked on the door, Romeo had gone, he died peacefully in his sleep. The nurse stayed with Romeo, the envelop was opened and the arrangements were set in motion.

Unfortunately, the children's hospice did not have a space to take Romeo till 8am and with no cooling mat at home, the family were aware changes were starting to show. As soon as it was possible Romeo went to the children's hospice so the family could spend more time with Romeo.

Mum remembers a touching act fondly when the paediatric palliative care consultant came in and saw Romeo, silently and just stood for a minute.

Mum also remembers the lead paediatric palliative care consultant sorted everything else out.

Romeo has samples in trials across the world, the family are still trying to find out the basis of his condition – a story yet to be concluded.



It is appreciated that you may have been affected by reading this story, if so, and you would like to speak with someone, please reach out.

This may be someone you know, or if not, you can call the Samaritans, they offer a 24-hour confidential emotional support, call free on **116 123** or email jo@samaritans.org.uk.

Just remember... you are never alone.



What Matters Most

- Listen to Parents – they know their child
- Start Palliative Care conversations earlier in journey - especially when parents ask to start the conversation
- Communication – regular and ensure families have the ways of getting in contact (envelope)
- Hospice – is not for all, this family felt trapped however appreciate it was difficult circumstances due to Covid
- Continuity of care – so important, you build relationships and trust
- Covid regulations impacted – PICU allowed two parents, ward only one
- Need to let parents know about vouchers and parking, earlier in journey



Things To Celebrate

- Support throughout our journey
- Amazing specialist children's palliative care team and children's community nursing team – just a call away
- ACP – development, delivery and adherence too
- Ronald McDonald support
- Letter in the draw – great to know it was there and info available when ready/ if needed



I can make a difference

Mum, Dad, big sister, Romeo and a little sister, were all supported by a wonderful array of family and friends. The amazing team from Sebastian's Action Trust, a wonderful Childrens Palliative Care Team, fantastic Community Childrens Nursing Team (CCNT) and those providing the invaluable continuing healthcare (CHC) package. They were never alone.



Mum now supports Hampshire and Isle of Wight Childrens and Young Adults Palliative and End of Life Care by sharing her experience, what matters most to your child, your family and loved ones when you find out your child has a life limiting condition. Everything that happens from identifying there is something wrong to losing your child and what happens in the days, weeks, months and years that follow. Everyone has a story and it is our privilege that Suzie has shared Romeo's with us, to help us understand a little more, learn lots more and make a difference.



Reflections from clinicians

Reflections from Paediatric Palliative Care Consultant...

I first met Romeo and his family whilst Romeo was on intensive care. Romeo was in a very difficult position, very fragile and dependant on ventilation support and circulatory support, attached to numerous lines and monitors. His heart was failing, his body was failing, but there was a distant hope of a transplant that might save his life. This distant hope was a carrot that kept being pulled further away from Romeo as time went on. Transplant teams across the UK could not come to a decision on his eligibility for transplant, asking for one set of tests, then another, discussing and returning with inconclusive decisions or setting unrealistic goals of weight gain that Romeo just could not achieve.

In the meantime, every week there was a new episode of infection, a stroke, a cardiac arrest that constantly set him further back as the carrot drifted further into the distance. This uncertainty and continuing glimmer of hope of transplant meant that Romeo had to be intensively treated for every episode of deterioration which meant remaining on intensive care, painful procedures, attached 24/7 to machines, not able to leave the unit, not able to enjoy each day. It also meant that we could do very little to improve his quality of life or meet his wishes.

Weeks and months went by of this stalemate until the news finally came from a second transplant team that he would never be eligible for a transplant. During this time we tried to support his quality of life on the unit with the introduction of the play team, hospice support, putting a play mat by his bed, getting his big sister onto the unit to see him. It felt so inadequate in a situation that I knew in my heart of hearts was not going to go well for Romeo.

Once the news of no transplant came it was devastating. In this loss and hopelessness however we were able to start working with the family to look at how to get the best out of Romeo's time he had left. We used the Children and Young People's Advance Care Plan to support this process. For this family, quality meant time at home, time together, with no hospital and no needles. We worked rapidly to find the best medicine to keep his heart going for as long as possible in the community, using a specialised drug called enoximone for the first time in the community in a patient like Romeo. It worked well, his heart managed to keep going for another 4 months. During this time we were able to support the family in meeting wishes for Romeo, enjoying time together at home, and having periods of near normality. He was able to attend the hospice for parents to go for dinner together, something that they had not done since he was born.

Completing the advance care plan was a natural process by this point. We had the relationship, we had the trust, we knew Romeo as the feisty, bold and determined little chap he was. We could, out of this support, direct the family, making shared decisions to ensure Romeo could be at home and would only receive the best care that was right for him, not harmful interventions that could not help him but might be offered at a time of crisis by professionals who don't know him but are trying to help.



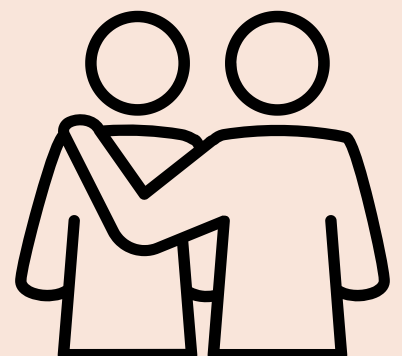


However, it was not an easy road. Romeo developed vomiting and episodes of breathlessness and agitation that required rapid response and regular symptom management reviews. One of our team (at that time just two consultants) saw him weekly virtually or face to face. We put in place a clear symptom plan and ensured his advance care plan was circulated to everyone he might come across in case he presented to hospital. Staffing in the community was depleted so we worked with the nursing team to get a care agency to support. This worked but the nurses were usually adult trained and not confident at times managing a child let alone one that was dying. There were gaps in nursing care which meant sleepless nights and anxiety for the parents and us as a team. As consultants we received calls out of hours and at weekends to manage symptoms and make decisions. This was all done unpaid and as good will as we had no wider team to support the community services in such a challenging case.

Each day for Romeo was uncertain and he could die at any moment from a heart rhythm change or further stroke. The issue of his nursing care came to a fore the night he died. There was a nurse in the house, but they were very anxious, underconfident, and struggled to support the family and contain their worries. Thankfully because of the work we had done with the family, they felt empowered and strong and able to be at home, lay Romeo on the floor in the lounge on the play mat and be with him as he died. The hospice was able to support with care after Romeo died but unfortunately there was miscommunication with the agency nurse and hospice team and a delay of several hours before he was transferred to the hospice. It was only the resilience, strength of the parents and support the community nursing team and palliative care team had put in that ensured Romeo died at home with his family in a place of acceptance, without fear or anxiety.

When I think back to his case nearly 2 ½ years on, I am pleased that Romeo died at home and with his family. I'm pleased we were able to work with the family during his time on intensive care. I'm pleased they had those months at home.

However, I'm frustrated we could not have got to know this family earlier. Romeo had a life threatening diagnosis from much earlier on in his life and we could have done so much more to give him a better life during those early times. I am saddened by those months in hospital waiting for decisions that maybe could have been made earlier if the right team was around Romeo from earlier on. I am saddened by the stress caused by lack of confident, competent nurses providing advice 24/7 during his end of life phase, and that the family had to reassure the agency nurse that was on as Romeo died, rather than the other way around.





Reflections from clinicians

Reflections from Lead Paediatric Palliative Care Consultant...

Romeo was a gorgeous little boy with incredible parents.

It is unusual for parents to make the initial request for palliative care involvement (rather than this being introduced by a health professional). But this highlights how dedicated his parents were. They recognised the value that palliative care could bring to their son's care and understood the need to hope for the best, whilst planning for the worst.

Having early involvement allows the palliative care team to build a relationship with the family, and to provide the personalised, holistic care that is so needed in times of uncertainty.

Every child under the specialist paediatric palliative care team is allocated a consultant who leads on their care, alongside the rest of the team to meet the needs of the child and family.

As a team we endeavour to make a difficult time a little easier.

Romeo's parents were amazing at every part of their son's journey – advocating for him at each step, always putting his best interests front and centre, making memories and above all loving him.

It was a pleasure to work on the same team as them looking after Romeo.

