the blend.

a mix of stories, advice and recipes for tubie newbies

Issue 3

WHOLESOME BLENDS

EFFORTLESS HOME FEEDING, HEARTFELT FAMILY MOMENTS.

Savour the ease of home tube-feeding with Wholesome Blends' 290ml shelf-stable pouches in four delectable flavours; Pork and Oats, Vegetarian, Chicken, and Cherry Cacao.

Designed to complement your regular family mealtimes and home cooking, our blended whole-food meals enrich the tube-feeding experience by bringing everyone back to the table.

Commercially sterile, Wholesome Blends is free from GMOs, soy, dairy, lactose, nuts and eggs. You won't find any added sugars, preservatives, additives or nasties in our easy-to-pour pouches. Just nourishment and love from our tubie family to yours.

Wholesome Blends products are NDIS-claimable and available within some hospitals and Home Enteral Nutrition Services (HENS) across Australia.

Wholesome Blends sells through all major medical distribution companies across Australia. For all international orders, we can ship direct to your home. Simply get in touch to arrange an international delivery.

Rediscover the joy of feeding your loved ones.
Visit **wholesomeblends.com.au** to explore our nourishing range and find your local distribution outlet.

www.wholesomeblends.com.au

@wholesomeblendsau **@wholesomeblend**

380 kCal
2
MILDLY THICK
WHOLESOME BLENDS
Nutritious Enteral Foods
Smooth pureed enteral food
Cherry Cacao
NET 280g
Free from
• Gluten • Dairy
• Egg • Soy • Nut
No preservatives
Australian Made
COMMERCIALLY STERILE
300 kCal
3
LIQUIDISED
WHOLESOME BLENDS
Nutritious Enteral Foods
Smooth pureed enteral food
Pork and Oats
NET 280g
Free from
• Dairy • Nut • Egg
No added sugars
No preservatives
Australian Made
COMMERCIALLY STERILE
310 kCal
3
LIQUIDISED
WHOLESOME BLENDS
Nutritious Enteral Foods
Smooth pureed enteral food
with chicken and carrot
Chicken and Vegetables
NET 280g
Free from
• Gluten • Dairy
• Egg • Soy • Nut
No preservatives
Australian Made
COMMERCIALLY STERILE
330 kCal
3
LIQUIDISED
WHOLESOME BLENDS
Nutritious Enteral Foods
Smooth pureed enteral food
Vegetarian
NET 280g
Free from
• Gluten • Dairy
• Egg • Soy • Nut
No preservatives
Australian Made
COMMERCIALLY STERILE

Kangaroo OMNI™ Enteral Feeding Pump

Coming soon, the future of enteral feeding

Kangaroo™ is by your side every step of the way

For over 40 years, the Cardinal Health™ Kangaroo™ Feeding portfolio has been at the forefront of innovation, offering a comprehensive range of enteral feeding products to support patients from the hospital to the comfort of their own homes.

ONLINE GUIDE

HECSA

**HEALTH EQUIPMENT
& CONSUMABLE
SUPPLIES AUSTRALIA**

SERVICE AS IT SHOULD BE

Founded in 2019, HECSA's guiding principle is to bring back old-fashioned service to the medical consumables industry.

Every decision we make is focused on solutions that provide better outcomes for you. Improving your comfort and health is our business.

- Continence
- Skin Care
- Wound Care
- Nutrition
- Respiratory
- PPE
- Janitorial
- Hospitality

I ❤ ndis

www.hecsa.com.au

1300 087 786

28 Proprietary Street, Tingalpa QLD 4173
Unit 1, 1-3 Civil Road, Garbutt QLD 4814

The Blend Issue Three was created in partnership with...

amsl medical

A SIMPLE patch

ausEE Inc.

AVANOS

blendtec

Carer Solutions

CardinalHealth

Children's Nursing Queensland

HECSA HEALTH EQUIPMENT & CONSUMABLE SUPPLIES AUSTRALIA

Hibi

Kathryn Lean Artist

Paediatric Feeding International

REALFOOD BLENDS

Tubiefun

WHOLESOME BLENDS

whole enteral

the blend.

Disclaimer
This resource is for general information and support purposes only. The information is not intended as a substitute for professional medical advice and if you have questions or concerns regarding your health or that of your child, please seek assistance from a qualified and licensed health professional. While every effort is made to ensure that the information contained in this book is accurate and appropriate, *The Blend* creators make no warranty of any kind, expressed or implied, and are not liable for the accuracy, currency, errors or omissions in the information contained here. All access to, and use of, the information is at the reader's discretion and risk.

Credits
The Blend is curated, written and edited by Melanie Dimmitt and designed by Edie Swan. The cover photo is by Samantha Humphreys. The recipe nutritional analysis was done, very kindly, by Kate Dehlsen.

Acknowledgement of Country
The Blend creators acknowledge the Aboriginal and Torres Strait Islander peoples of Australia. We acknowledge the Gundungurra, Tharawal and Garigal peoples, the traditional custodians of the lands on which *The Blend* was made. We pay our respects to ancestors and Elders past, present and emerging.

the blend.

contents

Parent stories

Cover story

Professional perspectives

Personal accounts

Features

22
TUBIE BEAUTY
When will we see feeding tubes on fashion runways and in makeup ads? We speak with three tube-feeding advocates who've got the inside scoop.

54
SQUAD GOALS
It can be taught. A family shares how they built a circle of tube-feeding-savvy supports around their child.

100
HAVE FEEDING TUBE, WILL TRAVEL
Come fly, cruise and caravan with a worldly bunch of travelling tubies.

134
GIMME FIVE
We ask a fun-loving crew what advice they wish they could give themselves at the start of their tube-feeding journey.

Recipes

Directory

128
What tubies want: a directory of go-to products and online communities.

A message from the editor, Melanie Dimmitt

Photography: Abbie Melle

They say the third time's a charm – and I like to think this third issue of *The Blend* is, indeed, a charming collection of reads. If you're new here or perhaps a returning reader, welcome. We're thrilled to be back and sharing more stories from tube-feeding people, families and professionals in this exciting and diverse space.

The Blend magazine exists because, back when my son's tube-feeding story began, a fellow parent's advice transformed our experience from nightmarish to nourishing. The tube-feeding community is, undoubtedly, one of the strongest and most supportive you will ever find – and you'll find it in every corner of the globe.

Our cover star for our third issue is Molly Humphreys, a five-year-old girl who, when our cover photo was taken, was just hours away from having her feeding tube removed. Molly's mother, Samantha, took this snap to celebrate what Molly's G-tube meant for their family, and says in her interview (which you can read on page 56), 'Molly wouldn't be what she is today without that tube, it was a huge part of her journey.'

> "The tube-feeding community is, undoubtedly, one of the strongest and most supportive you will ever find."

Through the work of advocates like Samantha and tube-feeding social media influencers Stephanie Kelly, Hannah Setzer, mothers Melissa Schlemmer and Grecian Martin, and father-son duo Robert and Chace Selby (who you'll meet in this issue), awareness is growing around our community. We're also starting to show up in more mainstream media. Our 'Tubie Beauty' feature (on page 22) showcases a trio of tube-feeding talents from the fashion and beauty industries, sharing their hopes for better representation.

Meanwhile, youngsters can now 'tube-feed' their toys with tiny, 3D-printed medical devices, thanks to the former nurse behind The Butterfly Pig, who you'll meet on page 70. And if you think this way of eating means the end of your travel plans, prepare to be proven wrong – and inspired – by the globetrotting families in our 'Have feeding tube, will travel' feature (see page 100).

Find all of this – and so much more – on the pages to follow. We adored putting this issue together and hope you are equally moved and enlightened by what's to come.

Much love,

Mel xx

melaniedimmitt.com.au
theblendmag.com
@melanie.dimmitt

REAL ~~FOOD~~ people, TUBE FED

www.whole.net.au

" hi, my name is kiki and i was the first whole tubie"

whole enteral

Glossary

ADHD (attention-deficit/hyperactivity disorder) is a neurodevelopmental condition characterised by heightened levels of inattention, impulsivity and hyperactivity.

Aspiration means accidentally inhaling liquid or food into the windpipe and/or lungs.

Blenderised food or a **blenderised diet** is real food, blended with liquid and put through a feeding tube.

Bolus feeding means large amounts of formula delivered through the tube.

Cognitive behaviour therapy (CBT) is a type of psychotherapy that can help people find new ways to behave by changing their thought patterns.

Cornelia de Lange syndrome (CdLS) is a rare genetic condition characterised by numerous physical, intellectual and behavioural differences.

Ehlers-Danlos syndrome (EDS) is a group of inherited connective tissue disorders mainly affecting the joints, skin and walls of blood vessels.

Emetophobia is the fear of, or anxiety around, vomiting.

Enteral feeding is a method of supplying nutrients directly into the gastrointestinal tract.

Epilepsy is a chronic neurological disorder characterised by the tendency to have recurrent seizures.

A **feeding pump** is a small, plug-in or battery-powered machine that controls the amount of formula being delivered through the feeding tube.

A **gastrostomy** is a surgical opening (stoma) through the skin into the stomach.

A **gastrostomy (G) tube** is placed through the skin of the abdomen straight to the stomach.

A **gastrostomy-jejunostomy (G-J)** tube is placed into the stomach and small intestine.

A **giving set** is tubing connecting the feeding container to the feeding tube.

Granulation tissue is fleshy projections formed on the stoma.

An **IV central line** is a catheter placed into a large vein, used to give medicine, fluids, blood, or nutrition.

A **jejunostomy (J) tube** is placed through the skin of the abdomen straight into the intestines.

A **lymphatic malformation** is a clump of abnormal lymph vessels that form a growing cluster of cysts.

A **nasogastric (NG) tube** starts in the nose and ends in the stomach.

A **nasojejunal (NJ) tube** passes through the nose into the small bowel.

The **NDIS** is Australia's National Disability Insurance Scheme.

The **newborn intensive care unit (NICU)** is a hospital care unit for premature and unwell newborn babies.

A **percutaneous endoscopic gastrostomy (PEG)** is a surgery to place a feeding tube.

Preeclampsia is a serious condition of pregnancy characterised by high blood pressure.

The **National Health Service (NHS)** is the publicly funded healthcare system in England.

Post-traumatic stress disorder (PTSD) is a form of anxiety disorder that's triggered by either experiencing or witnessing a terrifying event.

Postural orthostatic tachycardia syndrome (POTS) is a disorder affecting heart rate and blood pressure that can make you feel faint or dizzy.

A **stoma** is a surgical opening where a feeding tube can enter the body.

Total parenteral nutrition (TPN) is complete nutrition delivered directly into a person's vein, bypassing the gastrointestinal tract.

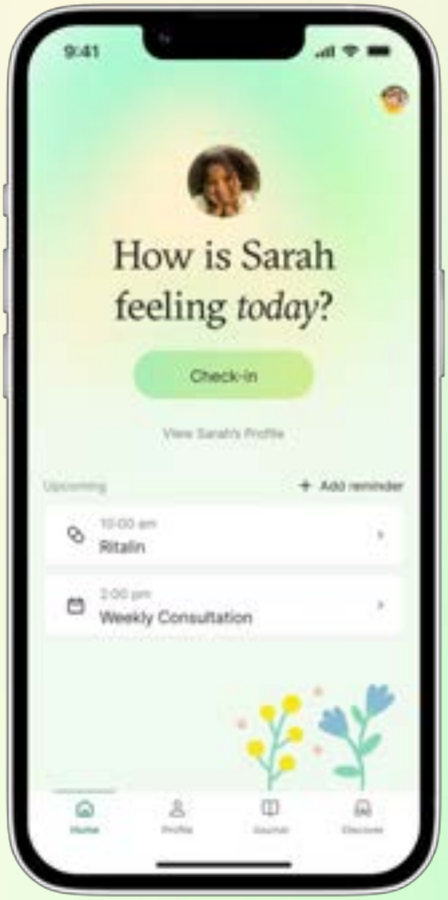
A **tracheostomy** is an opening created at the front of the neck so a tube can be inserted into the windpipe (trachea) to help you breathe.

Tetralogy of Fallot (TOF) is a congenital heart condition characterised by a combination of four cardiac defects.

VACTERL association is a disorder that affects many body systems. VACTERL stands for vertebral defects, anal atresia, cardiac defects, tracheo-esophageal fistula, renal anomalies, and limb abnormalities.

Hibi

Helping families to manage, coordinate & navigate their child's care.



Our AI-powered assistant is able to help with any question you might have about your or your child.

Hibi is an app providing families access to care management tools and expert guidance.

Try it for free today:

Featured contributors

Some of the talents behind *The Blend* Issue Three share why they love creating content around tube-feeding.

MOLLY BURMEISTER

Photographer, 'Tubie beauty', page 28

'Working with individuals from diverse backgrounds offers me the privilege of hearing their unique narratives which, in turn, allows me to create visual stories that amplify their voices and perspectives on a broader stage. I'm eagerly looking forward to continuing my journey of capturing people at their most genuine, because it's through these diverse and authentic portrayals that we can truly celebrate the beauty of humanity.'

KATHRYN LEAN

Artist, page 22, 76 and 99

'I believe that art should be representative of all human beings, so I really strive for my art to show tube-feeding in a way that is not often seen – the fear and the struggles, but also the possibilities it can give. I hope that sharing art and content about tube-feeding can give others permission to express themselves in whatever way that may be – and also give a bit of hope that life doesn't stop when tube-feeding begins.'

KATE THOMAS

Author, 'Making magic', page 84

'As someone who will most likely need a tube later in life, it's such a privilege to speak with others and learn the reality of what it's like to be a tubie. Stories about tube-feeding are so important, not just for a 'tubie-to-be' like me, but to dispel the myths around it and show that it's such a normal way of life.'

Our cover star, Molly, is photographed by her mother Samantha Humphreys, who you'll meet on page 56. Of this photo, Samantha says: 'I took a few snaps to mark the end of our tube journey, for my memories. This was the day before her operation to have her feeding tube removed.'

‘Underlying Growth’

Tubie Beauty

The images that shape our culture are starting to look different. But when will feeding tubes join the diversity trend? Three advocates in the fashion, makeup and modelling industries take stock of this changing scene.

Artwork: Kathryn Lean

American model Tyra Banks was right in saying 'perfect is boring, human is beautiful' – and slowly, slowly, the fashion and beauty industries are catching on. Calls for more diversity are (slowly, slowly) seeing disability better represented by brands in the business of aesthetics. Gucci Beauty debuted a fresh face with Down syndrome. Moschino sent a model with cerebral palsy down its New York Fashion Week runway. British Vogue featured a series of disabled cover stars.

Things are changing, but while we know around a fifth of the global population has disability, at last count, less than 1 per cent* of fashion and beauty models visibly belong to this cohort. In light of this minuscule number, is it any wonder we don't see feeding tubes on billboards, magazine covers or in fashion shows?

Tube-feeding interviewees of this magazine, Stephanie Kelly and Hannah Setzer, have respectively walked in Australian and New York City fashion week shows. However, while these flesh-and-blood talents are making their mark, if you Google 'tube-feeding model', you'll be directed to a 'tube-feeding simulator' manikin.

As a concept, tube-feeding is stuck firmly in the medical realm. We'll see people with feeding tubes on hospital walls, in sick kids' charity fundraisers and anti-smoking campaigns. But in an ad for a party frock, curling tong or non-clumping mascara? Never.

>>

Sunshine Coast-based model Anja Christoffersen finds it ironic that, when she was unhealthily thin – a look she says is still standard 'model material' – the nasogastric tube she had at this time prevented her from working.

'I once lost an international modelling contract because my hips were "too big" and my face was "too fat",' Anja recalls. 'Then I lost a ton of weight because a surgery that I had went wrong. I was at my absolute thinnest, which is actually exactly what the modelling industry wanted from me, but what they didn't want was the visible medical device.'

Anja, who has a rare condition called VACTERL, saw her feeding tube as a lifeline. 'It also shifted my perspective,' she says. 'I'd always had a disability – since I was born – and then all of a sudden I had a tube strapped to my face and people treated me completely differently. I was shocked.'

As the founder of Champion Health Agency – a talent agency representing people with lived experience of disability and chronic illness – Anja is now part of the solution to tube-feeding's image problem. However, she thinks the modelling industry has quite the dark motive for not representing this community.

'They're always going to be very sensitive about having feeding tubes because I think that, deep down, they feel like they caused them,' says Anja. 'I think the modelling industry feels that having a feeding tube on a model – especially a model that is thin – will attract the wrong kind of attention.'

"Tube-feeding is never shown as just, 'this is how you are and you can live a happy and fulfilling life'."

When Anja had her feeding tube, she says her modelling history saw many people – including medical professionals – assuming she needed it because of an eating disorder.

'It got to a point where my dietitian accused me of lying,' she says. 'They said, "You haven't had as many feeds as you're telling me you've had. I think that you want to stay this thin". I was trying so hard to gain weight and it wasn't working, and it was being blamed on me.'

Eating disorders, as Anja saw for herself while working in Europe, are not uncommon in the modelling world. And enteral feeding is, in some cases, used to treat eating disorders. But as Anja points out, this hardly represents the breadth of tube-feeding experiences.

'Tube-feeding is never shown as just, "this is how you are and you can live a happy and fulfilling life",' says Anja. 'It's always shown like, "you're near death and we need to make you fatter". It's not shown as a way of being, it's shown as a state of transition.'

Anja applauds the growing trend of people with visible disabilities turning up in fashion and beauty campaigns, but notes that feeding tubes – 'those things that so many people need to survive' – are left out of the picture. Her hope of this changing lies with social media influencers like Champion Health's own Stephanie Kelly (featured on page 92), who shares fashion and beauty content with her feeding tubes in tow.

'I think that will push the shift, because we're seeing influencers take over the modelling space,' says Anja. 'These influencers have consumer power and reach that brands cannot, from a business sense, afford to ignore.' >>

> "We're seeing influencers take over the modelling space. These influencers have consumer power and reach that brands cannot, from a business sense, afford to ignore."

Anja

Christoffersen

Millie Fleminton-Clare

Right now, UK-based Human Beauty seems to be one of the only makeup brands to have featured a model with a feeding tube. In their 2023 campaign, stunning photos capture the smiles of a woman called Ru B, flaunting a metallic silver eye-shadow alongside an NG tube taped to her cheek.

‘It was a non-negotiable that I would have a model with a feeding tube,’ says Human Beauty founder Millie Flemington-Clare, whose rare metabolic condition, cystinosis, meant she grew up with both an NG and G-tube.

‘It would have been a life-changing moment to have seen such a model in a beautiful makeup campaign. My feeding tube was a huge source of insecurity and I would love to see more representation – within fashion, as well. If I could see a lingerie or swimwear model wearing a feeding tube, younger Millie would leap with joy.

‘My personal journey and experiences have driven my passion for makeup and beauty. It’s not just about aesthetics. It’s about empowerment, self-love, and challenging stereotypes. I want to show that beauty comes in all forms, and makeup can be a transformative tool for building confidence and embracing one’s uniqueness.’

Ru B stars in Human Beauty’s campaign alongside what Millie describes as a ‘full rainbow’ of diverse models, including talent from the LGBTIQA+ community, models with disability and a friend of Millie’s who

“My personal journey and experiences have driven my passion for makeup and beauty. It’s not just about aesthetics. It’s about empowerment, self-love, and challenging stereotypes.”

wears her hijab as a Muslim – ‘which is also a very underrepresented community in the beauty industry outside of the UAE,’ says Millie. ‘If a brand like L’Oréal did something like this it would be received with an outpouring of press and called “groundbreaking”, when it’s just basic representation. It should be the standard.’

If big beauty brands want to represent the tube-feeding community, according to Millie, there’s nothing stopping them. ‘They can easily incorporate those with feeding tubes in their campaigns, or, even easier, they can work with influencers who have feeding tubes.’ A favourite of Millie’s is Megan Fisher, aka the Chronic Makeup Artist, who you can meet in Issue Two of *The Blend*.

‘I often talk about how most bullying or ableism comes from a lack of knowledge and a big part of this is due to the lack of representation,’ says Millie. ‘If more kids were exposed to those who are different from a young age, they wouldn’t act out or stare when seeing people with visual differences out in society.

‘I paid extra to hire models with different disabilities and if I can do it with my life savings – a very small budget – these major brands could do it in a heartbeat.’ >>

Human Beauty photography by Kaye Ford @fordtography

Amelia

Tang

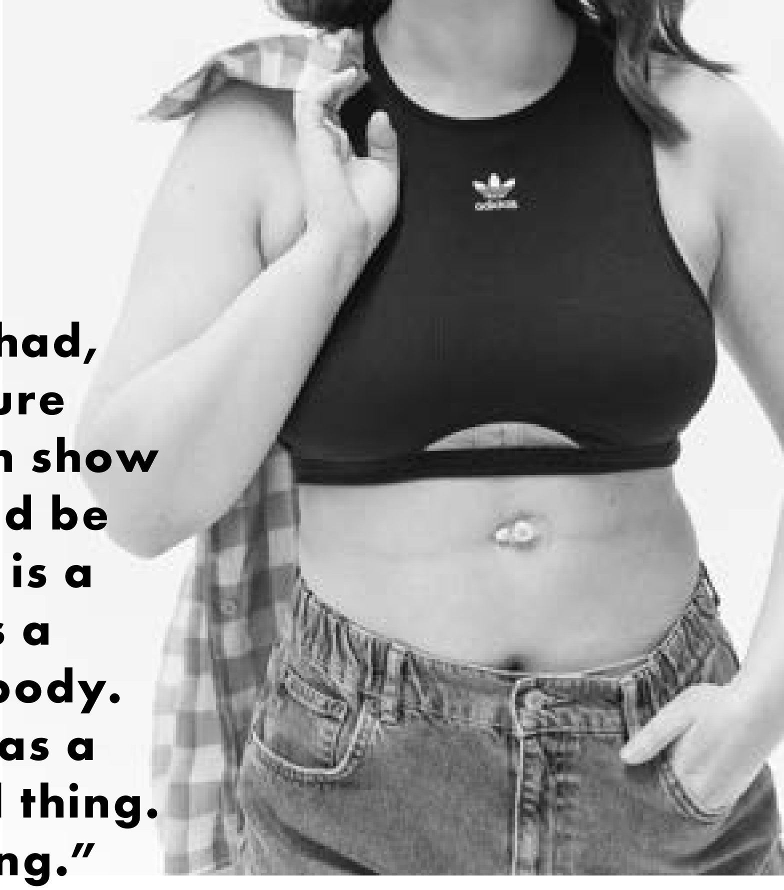
Millie found Zu B through the global, inclusive acting and modelling agency Zebedee Talent, which also represents Melbourne-based tube-feeding model Amelia Tang. Amelia has severe post-exertion malaise (PEM), a symptom of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). This is part of the reason they use a G-tube, but other causes are still being investigated.

'I'm not able to really eat orally right now,' says Amelia. 'I can swallow Coke Zero, I can suck on mints and I like to lick chips,' they laugh. 'You've got to get your flavour somehow!'

Amelia grew up acting and singing and, at a young age, was working on shows for the ABC and Disney Channel. At around 14, when Ameila's condition took hold, they lost the stamina for long days on set. In recent months, modelling has proven the perfect way for Amelia to get back in front of the camera, doing what they love – and doing it with their G-tube.

'In a job I recently had, I wanted to make sure that my tube was on show so that people would be able to see that this is a normal thing,' says Amelia. 'This is a neutral part of my body. I don't really see it as a good thing or a bad thing. It's a life-saving thing. It's as normal to me as my nose or my mouth. So I think that this should be on show, you know?'

Amelia believes we should all be able see ourselves in the images and stories that surround us. 'Growing up queer, it was really important for me to



> **"In a job I recently had, I wanted to make sure that my tube was on show so that people would be able to see that this is a normal thing. This is a neutral part of my body. I don't really see it as a good thing or a bad thing. It's a life-saving thing."**

see that represented in the media, so I know the importance of that,' they say.

'We, as a society, still view medical devices as something to feel sad about. There's not enough education and awareness around them. I think that if the everyday person saw what a positive impact medical devices have on people's lives, they'd feel very different about them.'

With Australian Fashion Week in their sights, Amelia also dreams of working with inclusive Aussie fashion brands JAM the label and EveryHuman, and mainstream offerings like Kmart and Peter Alexander.

'I'll certainly fight to get more tube-feeding models into fashion,' says Amelia. 'We do exist – and I'm hopeful that we'll get there.'

We'll wait, in that hope, for feeding tubes to take hold in the spaces we associate with beauty. For now, tube-feeding makes it possible for new, influential talent to show up, speak out and push for change across these industries. And that, in itself, is a beautiful thing.

Millie is offering readers of The Blend 20% off the entire Human Beauty range. Use the code **THEBLEND20** when checking out at humanbeauty.co.uk

Photography: Molly Burmeister @mollyburmeisterphotography

** 'The Fashion Industry Ignores Disabled Models. This Agency Is Doing Something About It.' Eliza Huber, 29 July 2020, Refinery 29. Accessed via www.refinery29.com/en-gb/2020/07/9938371/models-with-disabilities-fashion-zebedee-management*

Tube Nurse Specialists

Parent stories.

+ Robert Selby
+ Grecian Martin
+ Melissa Schlemmer
+ Sarah and Stuart Chignell
+ Samantha Humphreys

He♥rt warrior

When family life doesn't start the way you'd planned, fear takes hold. But this American father has found purpose, community, fun – and fame – chasing after his son on a path less travelled.

Who would've thought a selfie could see your family catapulted to stardom? Not Robert Selby. But in 2017, after posing with his toddler, Chace, in their bathroom mirror, Robert's snap captured worldwide attention. Why? Well, aside from being smile-crackingly cute, the selfie shares a unique show of solidarity from father to son.

Both Robert and Chace are featured bare chested, brandishing gastrostomy (G) tube buttons. But unlike Chace's feeding tube which, along with a scattering of scars across his torso, has been with him since he was a newborn, Robert's is only the top of a low-profile button, super-glued to his stomach.

'I just wanted to be one of Chace's biggest supporters – and show him that he's more powerful than he actually thinks,' says Robert, when asked why he risked his own skin to stage this particular shot (just a dab of superglue, he assures, does the trick without any lasting damage).

'I wanted to show him that just because he has a feeding tube and scars, it doesn't stop him from being a normal kid.'

After taking this photo, Robert posted it to Instagram and tagged Frobabies, an account that celebrates Black children and families. Overnight, Robert received a flood of messages.

'It just spread like wildfire,' he says. 'Not a day went by when I didn't have interview requests in my DMs. *Fox News* reached out and then they came to our crib and had us on one of their segments – and it just kept going and going and going.'

Emerging from the media storm, the duo were offered the opportunity to star in Apple TV's 2019 documentary *Dads* alongside Will Smith, Jimmy Fallon and Ron Howard. And despite sharing the cast credits with these and other Hollywood heavyweights, Robert and Chace are, quite literally, the poster stars of this film.

'When we're out and about, sometimes people see us and they're like, "Oh my gosh, I saw you in this documentary!"' says Robert. 'I can't believe it.'

In 2021 Chace lit up screens again, sharing his love for Robert in a segment celebrating Black fathers on the Oprah Winfrey Network. And now seven years on from that bathroom selfie, 10-year-old Chace is still rocking a G-tube and still advocating for his community. As is his dad.

>>

'We do whatever we can to shine more light on tube-feeding and Chace's heart condition,' says Robert. 'We've got an opportunity to bring a bit more awareness to these things and I want to give families a kind of calmness – a security blanket – you know? Something to look forward to.'

It was only after Chace was born, in October 2013, that his parents learned he has a rare heart condition called tetralogy of Fallot (TOF).

'We were about to leave the hospital when the doctors said that they could hear Chace had a strong heart murmur. They said this was normal – "most kids have it, so don't worry about it" – but when they ran some more tests, it was more severe than they thought. And it just went downhill from there,' says Robert.

At just a couple of weeks old, when Chace had the first of two open-heart surgeries, he took his time to recover. 'Sometimes kids can be stubborn, you know?' Robert smiles. 'The reason he got a feeding tube was because he was on a nasogastric (NG) tube and IV drip for months. He never developed that motor skill to actually work for a bottle. Plus, he was on the smaller side.'

The hospital Chace was in would only let him go home with a G-tube, not an NG tube. But Chace's mother, Chantay, wasn't keen on the idea of her baby being cut open again. >>

> **"We've got an opportunity to bring a bit more awareness to these things and I want to give families a kind of calmness – a security blanket."**

“I said to Chantay, what is the thing that we actually want most? And she said, ‘I want my baby to come home with us’. So I said, well, this is the best way for him to come home sooner than later.”

'She was not having it at all,' says Robert. 'But our insurance company had decided he'd been in hospital long enough, so time was against us at this point. I said to Chantay, what is the thing that we actually want most? And she said, "I want my baby to come home with us". So I said, well, this is the best way for him to come home sooner than later.'

The new parents brought their son back to Woodbridge, Virginia, where Chace would begin life tube-feeding three times a day. Before they left the hospital, Robert and Chantay were shown how to replace Chace's G-tube. However, when it accidentally fell out while Robert was on parenting duty, 'all that training went out the window'.

'I couldn't think of the first thing to do besides pick him up, grab his little feeding tube and drive to the nearest hospital,' says Robert. 'I'm calling his mum while driving with him in my arms and the seat belt wrapped around us, and all I remembered is, if it pops out, you've got like 10 to 15 minutes before it fully closes up.

'When I got to the hospital, Chantay called me back and was like, "you know you could have put this back in yourself", but it was just like how they teach you that when you catch on fire, stop, drop and roll. When that actually happens, you're panicking, you're not even thinking about that. So the very first time Chace's button popped out, I freaked out!'

Chace's second tube replacement happened in a calm, scheduled manner under the guidance of a nurse and, nowadays, Robert has no trouble helping Chace change his button. Along with much of their day-to-day shenanigans, he's even shared this process in their vlog series on YouTube, *The Life of Chace Elijah*.

'My son is like a little puppy,' Robert laughs. 'As soon as he hears my keys, he meets me at a door saying, "Dad! Let's go, let's go!".'

Dad's downtime only happens when he sticks a 'do not disturb' sign on his bedroom door.

'As a parent, you're always on the clock,' says Robert. 'There's no time out. And I understand you've gotta work, you've got your family, your friends... it's just a wave of things. But you've gotta re-energise. When I take an hour for myself, sometimes, I'm just in my room, laying on my bed, looking at the ceiling. And then I'm like, okay, now I'm ready. Let's go!'

When he's not with Chace, Robert works as a federal government security officer. Chantay also works in security, so the two tag-team between shifts and, although they're no longer together, continue to co-parent under the same roof.

'When we tell people that, they're like, how does it work? And we always say that we are adults, you know, it can work,' says Robert. 'Everybody has their own room and we all come together. We laugh, we joke, we cry, we talk about anything and everything. All Chace knows is love.' >>

These days Chace only has one tube feed through the night – and while the plan is for him to graduate off his G-tube, he's in no rush. Neither is Robert, who sees Chace's tube the same way he does his belly button. Chace still finds tube-feeding helpful for putting on weight which, as his dad describes, is an 'uphill battle'. However, Robert has chosen to look at his child, not the scales, when tracking Chace's progress.

'I don't care if he doesn't gain another ounce, so long as he's healthy and his heart is strong,' says Robert. 'Chace is like a magnet. When he gets into a room, everybody circles around him. He's a ball of energy – and I love it.'

> **"Chace is like a magnet. When he gets into a room, everybody circles around him. He's a ball of energy – and I love it."**

Chace is now an ambassador for the American Heart Association and, at a recent Heart Walk fundraiser, took on the role of TV presenter while interviewing participants and their pets. 'He'll tell you that he's shy,' says Robert. 'But when people talk to him – and when the camera is on him – that's when he shines his brightest.'

Robert, too, is working hard to raise awareness around family life with medical challenges. Fathers in particular, he points out, need more acknowledgement in this space. 'Even though society says a man should never be emotional and cry, I had emotional breakdowns. I had to see a therapist,' he says.

'I've also surrounded myself with like-minded and positive people, because I'm not a downer. I don't like to get stressed out or always be mad. It's not a healthy way of life. And my son keeps me full of energy and on my toes.'

To parents new to tube-feeding their kids, Robert says not to think of it as the end. 'This is only the beginning of what your child could be and the potential they could have. And don't get too down on yourself. You can get that way – and I understand why – but we are part of a community and we can all help each other. We're here to help pull you up. Just take it one day at a time and it'll be okay.'

@thelifeofchaceelijah
Chace Elijah
@TheLifeofChaceElijah

Following their lead

They say parenthood is a dance determined by our children. And once Grecian Martin started taking cues from her daughter, tube-feeding became the hero of their family's story. Here, the Perth-based content creator and mother of four retraces their steps to success.

When and why did tube-feeding first come into your life? So Riley, who is six, is my tubie. She's a 25-week, twin premmie who was born at 515g. The first time we were introduced to tube-feeding was when Riley and her twin sister, Hanna, were in the NICU for the first few months of their lives.

Both of them did really well, coming home on full suck feeds. But as time went on, we noticed Riley was aspirating on her bottles. She had come home on thickened formula with thickener also added to it, but once she started drinking water, we were never told to thicken this.

When she was around two-and-a-half, we fought with the ENT [ear, nose and throat] department at the hospital to check her swallow. Instead, they tried putting Botox in one of the notches in her throat to see if that would help to close over the part that she was aspirating from. For the next two years we were consistently telling ENT that Riley was still aspirating and choking, but they said, 'wait six months, wait six months'. It was always, 'just wait'.

It wasn't until our speech therapist picked up that her swallow didn't sound right that she was put on at least level-one thickener for fluids. Meanwhile, Riley had a horrible winter and stopped eating and drinking altogether. The doctors told us to force water and food into her, which was just horrible, as you can imagine. >>

How did you get from here to Riley having an NG tube placed? Our dietitian wrote us a letter to support us in taking her to hospital, in which explained that she was severely malnourished and severely dehydrated. So the NG was inserted then – and what a difference it made from day one. As scary as it was, it was the best decision. We had the NG for 10 months and over this time, ENT finally agreed to do a video fluoroscopy.

Those results were horrible, showing that Riley was silently aspirating on all levels of puree except at level seven. So they finally agreed that the PEG [percutaneous endoscopic gastrostomy] would be a definite thing for Riley and she was booked in. She got her G-tube in May 2023.

Your suspicions were right about Riley's swallowing. What advice do you have for other parents getting told that force feeding is the solution? I regret doing it as long as we did – you need to find someone that listens and supports you. Our dietitian told us, 'No, don't do that, because you're going to create negative associations. You're going to do more damage than good.' We went into the hospital with that letter and if we didn't have that letter, I don't think they would have listened to us.

I think as parents we have a tendency to second-guess ourselves. Like, do I really need to go into hospital? Is she really that complex? But you know what, these children are that complex and you just need to trust them. Their body is telling you something.

We're living day-to-day with our kids whereas, often, doctors only see them for those 10 minutes when they're assessing them in the emergency department. So find someone that listens.

> "I think as parents we have a tendency to second-guess ourselves. Like, do I really need to go into hospital? Is she really that complex? But you know what, these children are that complex and you just need to trust them. Their body is telling you something."

What does tube-feeding look like for Riley these days? All of her medicines and hydration go through her tube because it's unsafe for her to swallow liquids. For her first year of tube-feeding she was pretty much just formula fed, which did her wonders, but her oral eating really regressed – especially with the NG in. It's taken time to get her love of food back and her oral intake varies from day to day.

We never force her to eat but we always offer her food. She mostly just nibbles here and there when she wants to. If she asks specifically for something we'll make it for her even though she may just lick it or take one bite and then be done. It's all about that positive exposure to food. >>

You’ve got four kids. How do you integrate Riley's tube-feeds into family meals? Sometimes she has her feeds running while we’re all eating at the table. Other times, if she hasn’t eaten anything orally, she has it just after. Our youngest, Maisee, is two and loves helping with Riley’s feeds and meds. And we all sit together, even if Riley isn’t eating.

We’re lucky we can catch up on Riley’s feeds overnight if things don’t go to plan during the day. As long as she gets her calorie intake and hydration, it’s fine. We’ve learned to kind of go with the flow and adjust as we need.

I do hope we can get to the point where we’re on a blended diet instead of the commercial formula. I also hope that her love of food will keep growing. We’ve been told that due to her swallow being a neurological condition, she won’t outgrow it. We don’t think she’ll ever be able to drink water again or anything like that, but keeping that love of food there, that’s my biggest goal.

How do you tube-feed while out and about as a family? Let me just laugh for a second because, first things first, we don’t really go out very much with four kids – it’s hectic! But occasionally we do try, because I do like having that sense of normality.

When we go out we have a designated bag for Riley with all of her tube-feeding bits, rescue meds for epilepsy, nappies, wipes and other pieces in it. Her backpack from Tubie Fun allows her to tube-feed on the go and we just feed her wherever – literally. Sometimes we’re feeding her in the car boot.

Having Riley’s pump ready to go – primed with the formula in it – is a big help. We always carry extra 60ml syringes as well, just in case the pump fails or Riley needs some water. When the other girls have a drink, she gets one too, so she doesn’t feel left out.

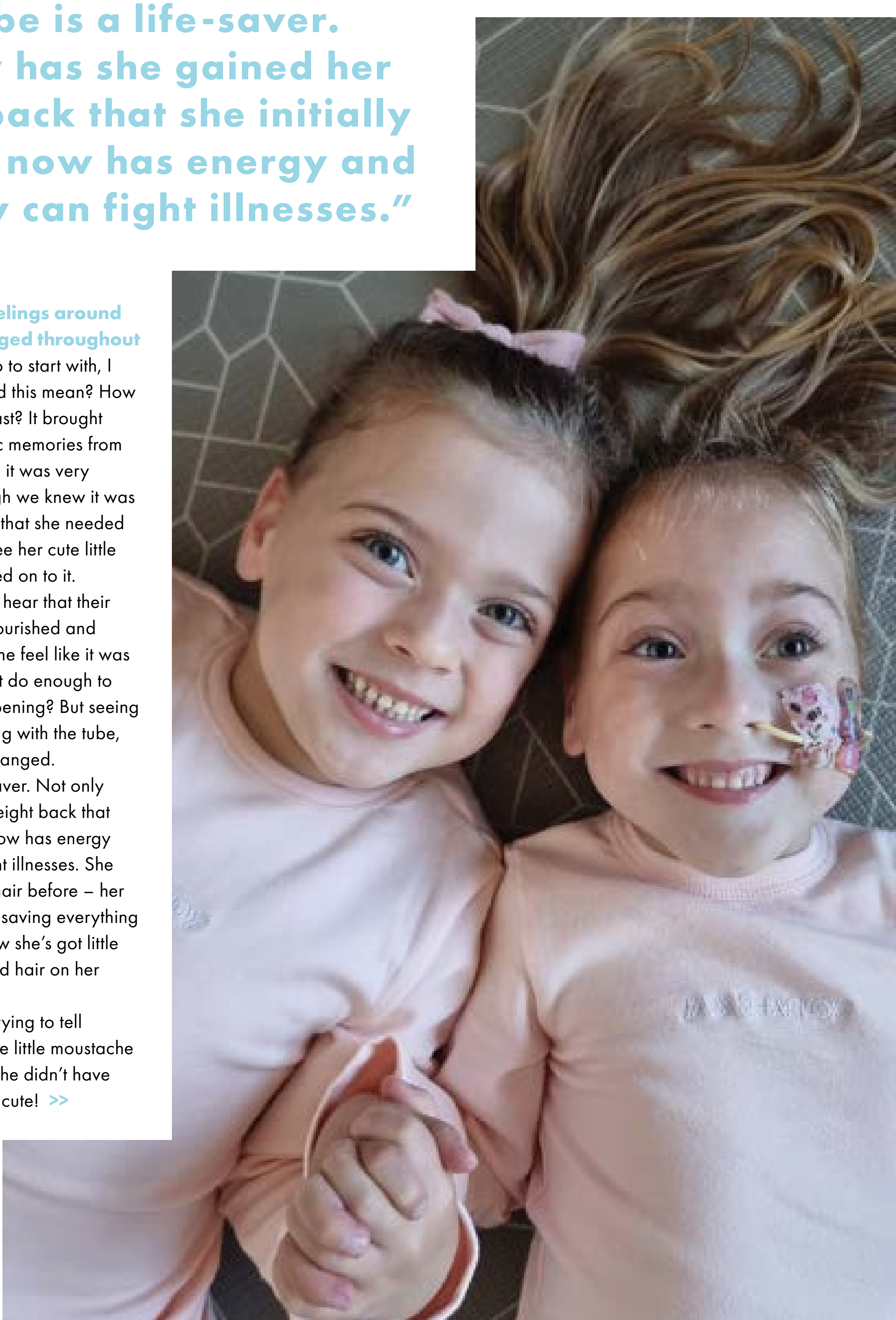
> **"That tube is a life-saver. Not only has she gained her weight back that she initially lost, she now has energy and her body can fight illnesses."**

How have your feelings around tube-feeding changed throughout Riley's journey? So to start with, I was terrified. What did this mean? How long was it going to last? It brought back a lot of traumatic memories from NICU so, to start with, it was very emotional. Even though we knew it was coming and we knew that she needed it, it was still hard to see her cute little face with the NG taped on to it.

No parent wants to hear that their child is severely malnourished and dehydrated. It made me feel like it was my fault. Like, did I not do enough to prevent this from happening? But seeing how much she's thriving with the tube, these feelings have changed.

That tube is a life-saver. Not only has she gained her weight back that she initially lost, she now has energy and her body can fight illnesses. She never had any body hair before – her body must have been saving everything to just survive – so now she's got little hairs above her lip and hair on her arms and legs.

It sounds so funny trying to tell someone that I love the little moustache that she's grown, but she didn't have one before and it's so cute! >>



> “Lots of kids have little nicknames for their G-tube or NG, which is really cute. Riley’s is called her ‘tummy tube’, and I think that helps.”

My son has only had his body hair since tube-feeding and it's only just occurring to me now while you're saying this! I love that you share this kind of stuff with your social media following. How do people tend to react to your tube-feeding related content? I get lots of messages saying things like 'thank you for educating us, we weren't aware of this whole other side of tube-feeding and the benefits of it'. Because I think it has that stigma where people think it's just really sick kids – or kids that are severely unwell and are not going to make it – who use feeding tubes. It's got those negative associations, so I like sharing how beneficial it is.

> "We just try to be positive about it and focus on why she has it."

I've also had people reaching out saying that they are a tubie family and they love watching us to get that sense of normality and see that someone else is going through it. And that's exactly why I started sharing our journey. If I can help one person feel not so alone, then I've done my job.

Much of what you post on social media is around body positivity. As Riley gets older, do you worry about how she might feel about her G-tube? Yes, but we just try to be positive about it and focus on why she has it. I was quite worried about bullying because she's now at school, but her classmates have been really supportive. They're really interested in it. However, I know this could change by the time she's eight, her older sister Adelyn's age.

Lots of kids have little nicknames for their G-tube or NG, which is really cute. Riley's is called her 'tummy tube', and I think that helps.

You also shine a light on our community through your podcast, RAWR, that you co-host with the lovely Amy Purling who we featured in Issue One of *The Blend*. What have you learned from conversations with other tube-feeding families? That tube-feeding is nothing to be ashamed of. Initially that shock does throw you a bit, but it does become our new normality. Parents will always say that you need to be prepared for anything and everything. You will feed the bed, you will feed the backpack, you will forget to unclip the tube. Everyone does! It will become second nature, so just trust the process.

You're never alone in this, even though some days it feels like it. It's so important to find your support network and this may not be in-person support, as we have found. Family and friends won't understand what you're going through because they're not living it every day. So lean on that online support – those families that do understand. Reach out to those who have been there, done this.

@growing_our_tribe

Hear more from Grecian on the new Tubie Talks podcast, wherever you like to listen to your pods.


ONE OF A KIND
cate.

Thriving success

On a tell-all trip down memory lane, Minnesota's Melissa Schlemmer reflects on how far she's come since her child had a feeding tube placed.

I recently found a notebook with the feeding log we used to keep for our then-newborn son, Christopher. It brought me right back to a time when we were at our wits' end, syringe-feeding him when he refused to take a bottle, writing down every single millilitre we were able to get him to swallow. There were days when his total intake across 24 hours was less than five ounces.

I was so desperate for Christopher to gain weight. I badly wanted to see the scale move in the right direction. I was aware that feeding tubes were not uncommon for children with our son's condition, but I was new to the world of medically complex kids and didn't know what I was doing.

When Christopher was diagnosed with the dreaded 'failure to thrive', I did what many worried mothers do and sought help from others who've 'been there'. I turned to social media, hoping that parents of children who share our son's rare genetic condition – PMM2-CDG – would be able to offer me some advice.

I was met with every single way to try and avoid a feeding tube.

The string of comments under my question post told me that peanut butter, avocado and milkshakes would solve my problem. But as my son's mother, I knew that there was zero possibility of him ingesting any of these high-fat foods.

I felt as though there was a 'we did it and we know you can do it' attitude when it came to avoiding a tube placement. Reading the responses of the proud parents, I immediately felt defeated. In my heart, I knew that avoiding a tube was nearly impossible.

When Christopher was nine months old – and the scale still wasn't moving – we met with a gastroenterologist. She asked if we wanted to be admitted to the hospital that afternoon for a gastrostomy procedure, not even entertaining the idea of dipping our toes into the world of tube-feeding by placing a nasogastric tube.

This situation was getting dire and although I knew that this was the only way for Christopher to thrive, I still felt shame. I felt as though I didn't try hard enough. I questioned myself and played every scenario out in my mind, over and over. >>

Maybe the milkshakes with heavy whipping cream would have worked? What if the peanut butter blended up with avocado was the solution? But I knew. I knew that placing the tube was our only answer and yet, it still felt like a failure.

I hate to admit that I was nervous to update the social media crew who confidently gave me advice on how to avoid a tube. They'd been so proud and certain that I, too, could avoid a tube placement for my child. I worried I'd be judged for not doing enough.

Honestly, though, if shed tears equaled effort, I tried hard enough. Tears as I shoved a syringe into my wailing child's mouth. Tears as I pumped and prayed he would take more than four ounces that day. Tears because I knew oral eating was not in his best interest. Tears because I felt like I failed him.

This was all so long ago and brings up many emotions, especially because my views surrounding the feeding tube have drastically changed.

> **"There is no shame, zero embarrassment and absolutely no disappointment. We are not failing over here, we are thriving."**

Christopher is now 10 years old. He has had a gastrostomy tube, a G-J tube, and now has a separate jejunostomy and gastrostomy. There is no shame, zero embarrassment and absolutely no disappointment. We are not failing over here, we are thriving.

There is nothing wrong with avoiding a feeding tube, but there is also nothing wrong with placing one. Avoiding a tube isn't 'winning'. Placing one isn't 'losing'.

I've learned that placing a feeding tube meant meeting Christopher's needs. A feeding tube is making sure he is fed, hydrated and given the necessary medications to stay as healthy as possible. A feeding tube is freedom from writing down every single calorie. A feeding tube is growing. It's loving him enough to know what's right for him. It's giving up my desires for him to eat cake and lick ice cream cones. It's setting aside the norms of society and living our way, unapologetically.

A feeding tube is so many things and failure isn't one of them. A feeding tube is living – and it's life-changing.

@ourrealrarelife
@our_real_rare_life


WE GET YOU · WE GOT YOU ·

Squad goals

How one family built a team of support around their tube-feeding son.

The eldest of Sarah and Stuart Chignell's five children is Eadweard, a cheeky teen who, due to his extremely rare genetic condition, has been tube-feeding since he was a toddler. He uses a MIC-KEY G-tube button, feeds with both formula and blended food and, according to his mum, is quite the mischievous trickster.

'When you see Eadweard laughing hysterically, you know he's done something to get a response,' says Sarah from their family home in Bendigo, Victoria.

'Although he has very little in the way of communication and motor skills, he's learned how to fiddle with his feeding tube to disconnect it from the pump. He'll roll in just the right way so that the tube goes behind his back, so if you only glance into his room, you can't actually see the big puddle of formula he's made!'

As one of only nine known people in the world living with infantile SCN1A encephalopathy, Eadweard's support needs are constant and complex. So much so that in the early years of his life, as Eadweard's only carers, his parents were struggling to cope.

'We once had six hospital admissions in a week,' recalls Eadweard's dad, Stuart. 'It was just exhausting and, for a long time, we weren't able to get support because the services around us took one look at what was involved and ran away.'

It wasn't until Australia's National Disability Insurance Scheme (NDIS) rolled out that Eadweard's family could access professional support. But even then, there were limitations.

'Once, when Eadweard was in hospital having a seizure, a paediatrician told me he wasn't sure that Eadweard would make it through,' says Sarah.

'I called the traditional support agency we were working with and asked if a support worker could collect Eadweard's formula from home, because it wasn't stocked by the hospital, but they said this wasn't within their policy. They said the support worker could be with Eadweard while I collected the formula, but I wasn't going to leave my child when there was a chance he might pass away.'

Fortunately, Eadweard's health has since improved – and so has his support system. By directly employing support workers through Carer Solutions, the Chignells have full control of Eadweard's team.

'We now have the flexibility to have conversations with our support workers and work out how they can help make life that little bit easier – and think outside the box on how to do that,' says Sarah.

'I can train Eadweard's support workers and say, "this is what we would like you to do". And when it comes to his nutrition, there are no legal requirements. There's no legislation saying you have to have a professional giving support

workers tube-feeding training or that parents aren't allowed to teach it. There's no red tape around it – it's all down to parental or client choice.'

Eadweard now has a team of five support workers, all expertly meeting his daily needs. 'Generally, our support team is better than us at doing Eadweard's tube-feeding,' says Stuart. 'They make sure the tube is connected before they turn the pump on!'

One of Eadweard's support workers, Katherine, has even found a fix for his trick of disconnecting his tube. 'Instead of running it around his waist and then out to the pump, we thread it out of the top of his shirt sleeve,' says Sarah. 'He hasn't discovered a workaround for this yet, but he's got plenty of other tricks, believe me.'

Carer Solutions

This story was made in partnership with Carer Solutions. Find out about their unique Direct Employ service by visiting carersolutions.com.au or giving their friendly team a call on 1300 729 839.

Meet a member of Eadweard's Carer Solutions support team, Katherine

'Working with Eadweard has taught me that tube-feeding is not as daunting as it seems. A feeding tube is not as fragile as people might think. You can handle it without it coming out, and moving it around doesn't hurt Eadweard, either.

'When Eadweard starts laughing, you know he's done something he shouldn't have. He's so cheeky – that's just him – and he gets the biggest joy out of causing inconvenience! I don't think a lot of doctors give kids like Eadweard enough credit. It's been mind blowing to learn his level of comprehension, because he's very, very switched on.

'I absolutely love working with Eadweard. I do feel sorry that he has struggles, but he doesn't seem to let them get to him. He's just such a happy boy and it's a joy to work with him.'


Molly

Pumped for change

When Samantha Humphreys' baby was born in a bundle of uncertainties, clarity was not delivered by doctors. Social media helped her discover her daughter's diagnosis, master her feeding tube and, eventually, wean her off it. Now, Samantha is sharing her story – and helping tube-feeding families the world over.

Molly Humphreys had grown impatient with her feeding tube. Delays are part and parcel of her rare genetic condition – Cornelia de Lange syndrome – so she was late to walk, but skilled in the art of dashing about on her knees, all while dragging half her body weight around in the form of a feeding pump.

This toddler was no longer willing to sit still in her highchair for hours on end, waiting for her tummy to fill. She had places to be and things to do, so that pump was just going to have to come along for the ride.

'We had it tied to everything,' laughs Molly's mum, Samantha. 'She was in her walker with it. She even had it attached to her little trike. Molly was getting so frustrated with being plugged into the pump and that was our main reason for weaning her off her tube. It was holding her back.'

Molly is now five, leading a busy life of sandcastle building, strawberry picking and schoolwork. Physically and cognitively speaking, she's keeping pace with her typically developing peers. Her main challenge, Samantha says, is anxiety.

'That stops Molly doing a lot of things. She's selectively mute at school, so she hasn't ever said one word in her two years there. She also won't eat, drink or move around the classroom without help. She's got these challenges, but she's happy in herself.'

The Humphreys family – Molly, her parents, brother Logan, 10, seven-year-old sister Evie, and two pet axolotls – call the county of Suffolk, an hour northeast of London in the UK, home.

Molly's older sister, Evie, is autistic, 'so it's almost like we're on a different path', says Samantha. 'Our girls are different and that's fine. We actually think that they're way more interesting than other kids. They've got such personalities to them.'

Having spent her baby and toddlerhood with both a nasogastric (NG) and gastrostomy (G) tube, Molly has been feeding tube-free for over two years. But were it not for Molly's own tenacity, her mother's advocacy and a pandemic, this may not have been the case. During the UK's Covid lockdowns, Molly transitioned from seven tube-feeds a day to only eating orally.

> **"Every time I see her eat, I'm still a little bit amazed. I never thought she was going to come off that tube."**

'I feel like if we hadn't suggested doing this, no one else would have,' says Samantha. 'You'd think the NHS [National Health Service] would be like, "right, let's see if this kid can come off this tube". But they were quite happy for her to just keep being tube-fed. There was no support or weaning programs. Our dietitian didn't have any weaning advice, she had to make it up on the spot.'

After slowly dropping her tube-feeds, by the time she was two-and-a-half, Molly's paediatrician said that if she went three months without using her tube, she could go on the waiting list to have it removed.

'We got a call for the surgery just before Molly's third birthday,' Samantha recalls. 'She's actually my best eater now and every time I see her eat, I'm still a little bit amazed. I never thought she was going to come off that tube.' >>

Back when she was pregnant with Molly, Samantha sailed through her 12 and 20-week ultrasounds. Then at 36 weeks, reduced foetal movements and a severe migraine saw Samantha admitted to hospital. 'Because my mum had a history of preeclampsia, they wanted to check me over and do a scan of the baby,' she says. 'That's when they realised that Molly's head was only measuring at 32 weeks and it all went into panic stations.'

At 37 weeks, Samantha was induced and Molly was born, healthy and crying.

'But when I went to feed her, her jaw was locked shut,' says Samantha. 'I breastfed my other two babies, so I knew what I was doing. It wasn't like she had a bad latch, she just couldn't open her mouth. I fed her drops of breastmilk and could barely even get a tiny syringe in there.'

Along with a severe tongue and lip tie, Molly had an undiagnosed submucous cleft palate. She also had terrible reflux, as her family would discover after Samantha and three-day-old Molly were sent home on a two-hourly feeding regimen. They returned to hospital a few months later when Molly developed bronchiolitis, RSV and then pneumonia.

> **"It wasn't like she had a bad latch, she just couldn't open her mouth. I fed her drops of breastmilk and could barely even get a tiny syringe in there."**

'That was the first time she threw up brown stuff – the lining of her throat and stomach,' says Samantha. 'Because she'd been in pain all those weeks with reflux, she just point blank refused to ever take a bottle again.'

At 12 weeks, Molly had an NG tube inserted and quickly developed a knack for pulling it out. She didn't like face tape and would tug at it in the night, causing great anxiety for her mother. Often Molly would wake up with her face covered in tape – evidence of Samantha's desperate attempts to keep her tube in place.

'That's why we were begging to have the PEG [percutaneous endoscopic gastrostomy] operation, because I was like, I can't live like this,' Samantha recalls. 'I'd go to change Evie's nappy and turn around and Molly would be without her tube. In the week before her operation she had that tube out every single day and putting it back down again was horrible.'

Molly had an NG tube for nine months before a respiratory doctor wrote a letter recommending she have a G-tube. Meanwhile, she continued to struggle with reflux – but not your textbook kind.

'Part of Molly's mystery is that she throws up this mucus stuff – it's not pure reflux,' says Samantha. 'You know kids' toy slime? The texture is like that. No one could work out where it was coming from and from the minute she was born, she just threw that up. It got worse and worse until every time she had something go in her mouth, she'd bring it out.'

Samantha's emetophobia – a fear of vomiting – certainly didn't help.

'I was a mess,' she says. 'I did two rounds of CBT [cognitive behaviour therapy] to try and treat it. When I explained our situation to my therapist, he said, "oh, this is going to be hard. Normally what I'd say to people is, okay, you're worried about vomit, but how often does vomit happen in a year for a child? But you're having exposure therapy every single day".'

Medication was the solution for Samantha, just as it was for her daughter. Soon after Molly turned one, while battling a bout of chest infections, a doctor put her on a long course of antibiotics.

'It was around Christmas time, so we let her have some Christmas dinner and she started having little nibbles of food and actually keeping it down,' says Samantha. 'She wasn't bringing up as much mucusy vomit. We told her respiratory team, they put her on an ongoing low dose of this antibiotic and things started to change.'

After three months on that antibiotic, the pandemic hit, lockdowns began and so too did Molly's DIY tube-weaning regime.

'Lockdown was amazing for her, because she didn't get ill,' says Samantha. 'We were all just at home, in our garden, with far less social pressure. I didn't have to worry about people staring at Molly or Evie so I was more relaxed and we had that time to not be so worried about the future. We were just living in the now.'

Month by month, as Molly dropped each of her seven daily tube-feeds, her taste buds explored food for the first time. Sharp flavours proved tricky – and taking her medicines by mouth was another challenge – but nowadays, she's an expert at self-administering.

'I just put her medicine syringes in a little bowl for her and she gets a syringe, pops it in her mouth and then goes for the next one,' says Samantha. 'Giving her back some control was really good for her.' >>

Once she was off her tube – and after 18 months of her antibiotic – Molly had another medication breakthrough. While attending a Cornelia de Lange syndrome conference, a doctor suggested she try a common asthma medicine, montelukast, that would get rid of her mucus issues for good.

'So now there's nothing stopping her with food!'

Samantha has since posted about this medicine on social media and, as a result, has heard from other families that have found it to be 'life-changing'. She remains, as ever, a fierce advocate for the tube-feeding community.

'Molly wouldn't be what she is today without that tube, it was a huge part of her journey,' she says. 'Yes, it's scary and it feels like a huge jump in the medical world because you've suddenly got a child with something in them that might be permanent. But it's not something to be fearful of.

'Everyone always goes, "oh, I couldn't do that". But like any parent that's never changed a nappy or done potty training, when the challenge comes to you, you do it. Tube-feeding isn't scary, it's just a process you've got to learn. It's a good thing.'

While learning the process of Molly's tube-feeding, Samantha and her husband, Martin, divided and conquered. Martin took care of then two-year-old Evie, while Samantha set up camp in Molly's room. And this wasn't the first time this couple had been hit with a hard knock. Just before Evie turned one, they suffered a traumatic miscarriage.

'After we lost our baby boy we had a really wobbly year and we had to do a lot of repairing on our relationship,' says Samantha. 'Once we'd been through that, when we were then faced with Molly's hospital admissions and being apart, it was kind of like, okay, we can do this, we're a team. But it wasn't easy. I can definitely see why people fall apart or lose themselves.'

Samantha says that in her experience of the NHS, very few professionals are trained to support parents with tube-feeding. 'There was no dedicated team of tube-feeding doctors, just social media. I basically learned everything I needed to know from a Facebook group – from other parents – and that's just how it is.'

Social media also played a major role in discovering Molly's diagnosis. When Samantha came across the Facebook page of a mother whose son has Cornelia de Lange syndrome, she was astounded by the boy she saw.

'He walks exactly the same way that Molly walks, they have the same mannerisms, they even look similar – he could have passed for her cousin! And I just thought, oh my goodness, this is finally it.'

One of Molly's doctors, however, brushed off the idea because Molly doesn't have a unibrow – a typical feature of Cornelia de Lange syndrome. This doctor was only familiar with classical presentations of the condition, which include severe cognitive and physical delays.

'I said, "well, people with this syndrome are not all the same",' Samantha recalls. 'Molly's doctor was wary of sourcing information from social media, but to satisfy my suspicions, they agreed to refer us to genetics.'

A few months later, there was no arguing with the results of Molly's blood tests.

'That doctor didn't look me in the face for so long,' laughs Samantha, who now shares generously about her family's life on social media in the hope of helping others. 'A diagnosis changed everything for us, so I'm quite passionate about this stuff.'

Having previously enjoyed working in property management, Samantha is happy to have a project outside of parenting – and her talent for photography comes in handy for creating content that keeps her growing following informed and inspired.

For other parents who want to be strong advocates for their children, she has this advice:

'Doctors can be quick to say that something isn't going to work. So I always say to people, go in with what you would like to happen and if they say no, ask them, why not? Give me a reason why not. And if it's still a no, say, can I trial it for a few months? If it doesn't work by then or if it's not shown improvement, fine. But we've tried it.

'I'm that person that doesn't complain if I get a bad dinner at a restaurant, so I used to be really timid at medical appointments and be like, "oh, okay, never mind". But now I've gained that voice. Even though it's really uncomfortable, you have got to gain that voice.'

> **"Molly wouldn't be what she is today without that tube, it was a huge part of her journey."**

@thehumphreysdreams

Professional perspectives.

- Ashleigh Mitchell & Dr Tessa Taylor
- Mary Jenner
- Robyn Wortel
- Hilarie Geurink
- Dr Chris Elliot

Keen to wean?

Two experts share their advice on making the transition from tube-feeding to oral eating.

Between the collective caseloads of dietitian Ashleigh Mitchell, the director of Nourish Paediatrics, and Paediatric Feeding International's Dr Tessa Taylor, hundreds of children and their families have been supported off their feeding tubes. How, you ask? Here, they answer.

When is it time for a child to wean off their feeding tube?

Ashleigh Mitchell: Deciding if and when to wean is very individual and needs a multidisciplinary approach – which could involve doctors, speech pathologists, physiotherapists, occupational therapists, psychologists and dietitians. Weaning requires consideration of the child's medical condition, their ability to eat and swallow safely, their growth, nutrition and hydration, along with their overall wellbeing and motivation. It also has to be the right time for their support network.

Tessa Taylor: First, a child must be cleared for swallowing safety to eat or drink orally, or to learn the skills they need to successfully participate in a swallow study. They also need medical stability and clearance – which might include testing for food allergies, or an endoscopy – and treatments for medical or physical factors. After that, the earlier and younger, the better.

What does tube-weaning usually look like and how long does it tend to take?

TT: Tube-weaning needs to be individualised for the child and family – and I've found substantial progress in eating and drinking skills can be achieved quickly, in a matter of days. My program sees tube-feeds reduced gradually as the child succeeds, without relying on hunger. Mealtime skills like using utensils, cup drinking, and chewing are taught. Food texture and independence in taking medication are increased. A wide variety of healthy foods from all food groups are used and, after we figure out what the child needs to be successful, we can also practise meals away from home, in places like cafes and daycare.

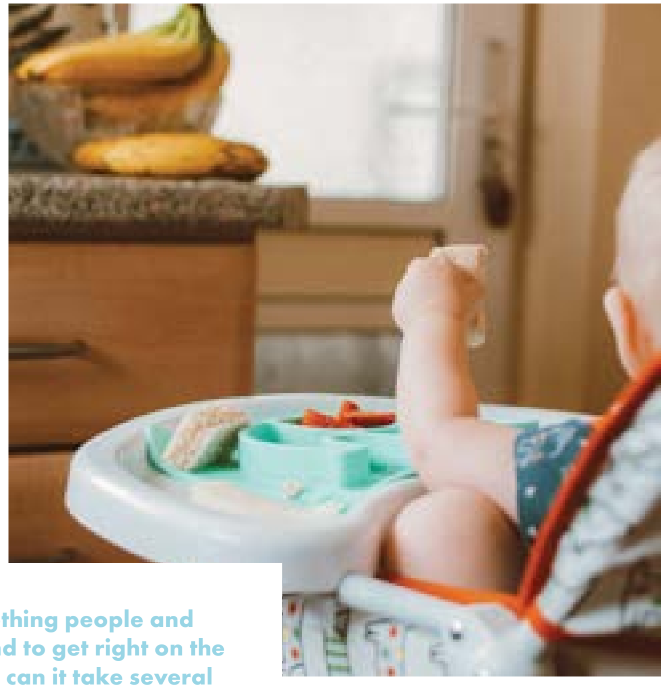
AM: There are lots of ways to wean. After discussion with a child's multidisciplinary team, I consider their nutritional needs, eating ability, food preferences, family routine and goals. We then aim to provoke appetite by reducing a proportion of tube-feeds. Food is offered first and the feeding tube may be used as a 'top up' providing what hasn't been eaten.

I work with families to ensure the foods being offered to their child are nutritious and high in energy and protein, give them a plan for balancing tube-feeds with food intake, and monitor their nutrition status. As for the timeline… how long is a piece of string? We reduce tube-feeds gradually as oral intake increases. There are so many factors involved, so it varies widely.

What are some common challenges that can arise while tube-weaning?

AM: From a dietitian's perspective, weight loss and a limited variety of food intake is common while tube-weaning. It takes time to learn to chew, swallow and eat – and becoming familiar with textures, flavours and smells can also be challenging. Ensuring mealtimes are positive – without pressure to eat – is very important. And regular monitoring of growth, blood tests and intake helps the child stay nourished during the process. >>

> **"If it's safe for them to swallow, they may do messy play with food. The aim is to de-medicalise tube-feeding and socialise at meals."**



I like to set children up for weaning from the time the tube goes in. There's a lot that can be done while tube-feeding to maintain the connection between feelings of fullness and learn about the sensory and social experience of eating. A child will learn about the process of eating if they are sitting with others eating, for example, at the table, a picnic or daycare.

We may administer the feed from a pump placed behind the child while they play with a spoon or, if it's safe for them to swallow, they may do messy play with food. The aim is to de-medicalise tube-feeding and socialise at meals.

TT: Initially, when oral eating and drinking skills are very new to the child, balancing how long it takes them to eat their meals with the amount of food and drink they need to have is critical.

Similarly, factors in meals such as texture, solid-to-liquid ratio and volume must be carefully analysed and individualised for the child if vomiting is a concern. Medical setbacks, like illnesses, surgeries or uncertainties that may be impacting meals, can also be a challenge.

Is this something people and families tend to get right on the first go – or can it take several attempts?

TT: Yes, they can get it right the first time around – especially with younger ages and medical stability. However, children may need a second go to reach the goal of chewing full, regular-texture meals.

AM: Think of it like learning a new skill. Sometimes you pick it up straight away and other times it takes trial and error. I try to encourage families to celebrate small steps towards eating rather than focusing on the end goal which, for some, may be tube removal.

What tube-weaning success story has really stuck with you?

AM: There are a lot of children and families that have stuck with me over the years. I have known some from birth and early childhood until they are taller than me and transitioning to adult services.

I had the pleasure of seeing a few have large medical breakthroughs leading to rapid tube-weaning, seeing children go from eating almost nothing to feeding-tube removal. The joy the families had when sharing this news is something I will never forget. Reflecting on these journeys is making me emotional right now!

TT: What's most touching is seeing so many 'firsts' – not only during the tube-weaning program, but in updates from the families after. With all the complexity and hard work that goes into it, it's so rewarding to finally see a child learn to take their first independent bite with a spoon, first chew, and experience so many different foods for the first time. A first for me recently was teaching a child to use chopsticks!

Families also report so many benefits beyond eating, like getting haircuts or allowing toothbrushing, or improved self-confidence. All this after being told their child 'can't' or 'isn't ready'. Thankfully, parents don't have to do this alone or wait. Effective support is available.

---

nourishpaediatrics.com.au

paediatricfeedingintl.com

RECLAIM THE JOY OF MEAL TIME

Our international consultancy services provide comprehensive and individualised assessments and treatments that work for children experiencing paediatric feeding challenges, including tube weaning and ARFID. We are dedicated to delivering high-quality services and supporting families through their journey. With our guidance and expertise, families can feel assured that their child receives the best care.

- ✓ 50 years of evidence backing
- ✓ Works quickly (in days, weeks)
- ✓ Intensive, In-home
- ✓ Tailored for your child and family
- ✓ Gradual tube reduction
- ✓ Wide variety of healthy foods
- ✓ Teaches independent skills (utensils, cup drinking, chewing, medication)
- ✓ Direct, high level of parent support and help
- ✓ Meals away from home and with other caregivers
- ✓ Funding available

Paediatric Feeding
INTERNATIONAL

Free overview with fillable checklist, references & links to resources

PaediatricFeedingIntl.com **DrTaylor@PaediatricFeedingIntl.com** Double Bay, Sydney, NSW, Australia

Child's play

Mary Jenner shares a home in Sacramento, California, with her husband, young daughter Josie, and a dozen 3D printers. The former nurse and founder of online store The Butterfly Pig – which includes a medical toy boutique – tells us how she's taking tube-feeding representation into a whole new dimension.


SA
PEN

Why is inclusion something you're passionate about?
When I was working as a nurse I started in paediatric oncology, where I noticed a lot of my patients found the experience easier if they had things to represent them. That's what got me realising that we don't have much representation for medical differences out there. The world has been pushing for more diversity and inclusion, but not so much for medical inclusion. There's great work in progress, but it could be better.

What's it like to work on paediatric oncology wards?
I didn't have a kid at the time, so mentally it was a little easier for me. But oh my gosh, the kids on those wards are amazing. They're going through the hardest time and yet those floors are so positive, which many people wouldn't really realise.

Kids don't really get depressed. With the older teens it was a little harder, but the younger kids would go about their day and they were happy. They'd want you to have tea parties with them – it was the best experience.

You began crafting toy medical devices while working with these kids. What did those toys look like? If my patients had their teddy bear, I'd give it a pretend IV [intravenous] drip and I'd make all sorts of things out of bandages and bits and pieces. One of my patients was about three-and-a-half – the same age my daughter is now – and I remember her wanting me to do everything she needed done to her on her teddy bear first. This made the whole process so much easier. She could see what I was doing and knew what to expect, so it wasn't so scary.

What you're describing there is a form of 'play therapy', which your toys naturally promote. Can you tell us how this works?
There are trained 'play therapists' who help with all sorts of things through play, but anyone can use toys to help teach kids about a medical procedure before it happens. During the procedure you can use toys to help distract kids or encourage them to get through it. And then afterwards, they can continue to help kids cope.

I've had some parents reach out to me after their child went through a traumatic medical experience. The child was okay, but they wanted their doll to have an endotracheal [breathing] tube so they could process what had happened to them.

It's hard for kids to talk about their medical experience, but when they play with toys, just by watching them explain to their doll, 'Oh, this is going to hurt', you can see what scares them or how they feel about different procedures.

> "It's hard for kids to talk about their medical experience, but when they play with toys, just by watching them explain to their doll, 'Oh, this is going to hurt', you can see what scares them or how they feel about different procedures."

When did you get serious about making toy medical devices?
It was during my maternity leave, mid-pandemic, and I was in a mum group on Facebook where somebody asked, 'Hey, does anyone know where I can get a doll-sized cochlear implant?' I've always done crafty things on the side – like making miniatures out of clay – so I said I could make one.

I moulded a little clay cochlear implant, sent it to the mum and she said it was great. She posted on social media, a couple of other mums reached out and then I started getting more requests. >>

> “Parents have told me that their kids are just so happy to be represented. I’ve been tagged in some videos on social media showing kids opening their gifts and squealing. It’s very cute.”

I couldn’t make everything people wanted out of clay and that’s what got me thinking about 3D printing. I have some experience with web design, so I downloaded and taught myself CAD [computer aided design] software and bought a 3D printer. And that really opened up the realm of possibilities of what we could make. We have 12 3D printers now.

You have a whole team of printers! Yes, a little factory! And it’s all happening from my house. During the lockdowns my parents moved up here and when my dad saw what I was doing – he’s a retired engineer – he was like, I think I could help you with this. He now has a couple of printers at his house and helps design things, too.

Take me through the process of making something really simple, like a toy G-tube button, and the process of making your bitsier toy IV pole with a feeding pump and gravity bag attached...
With the G-tube button we just have to 3D design it and, once it’s printed, we might have to make a couple of changes to it to get it right. On average, we probably change things around 10 times before we’re satisfied with the design. Once we have that, we set it up on the printer, it prints, then we tidy it up and then it’s good to go.

For bigger pieces it’s the same process for designing, but we probably do more renditions because we have to make sure stuff fits together. I make the stickers – like the ones on the feeding pumps – using [design platform] Canva. The gravity bags are made with a vinyl press. There are a lot of steps, but it’s a lot of fun!

How long would it take to make a G-tube button versus your IV pole and pump set? One G-tube button probably prints in 40 minutes. Then the IV pole – that whole set – gosh, that would probably take about 10 hours.

I can see why you have 12 printers. What are your products made out of? We mostly 3D print using a filament material called PLA [polylactic acid]. It’s actually a plastic alternative – like an eco-friendly plastic – which is typically made from corn, so that’s really neat. Then the flexible products like the pluggable G-tube are made from a medical-grade TPU [thermoplastic polyurethane].

So real feeding tubes could probably be 3D printed, yeah? Probably! Human organs – like stomachs and bladders – are now being 3D printed, which is really cool.

How did the medical device brands who make real feeding pumps – like Moog – feel about seeing their products in miniature? They loved it. I'd changed the phrasing on the stickers so instead of Moog, it said 'Food', but their team reached out and said they actually wanted me to use their phrasing. They sent me all their artwork and I recreated the label to look exactly like theirs.

Are your products showing up in many hospitals? Yes, absolutely. A lot of Child Life Specialists that work at hospitals or independently are reaching out. Their role is to advocate for a child and support them through their treatment – and they are so excited that these toys finally exist.

Many of them were crafting their own, which was very time consuming, and they were buying the supplies with their own money. We opened a Child Life Specialist fund application because I know they don't get as much funding as they should. We also have a separate fundraiser – a GoFundMe campaign – so people can donate our medical toys to Child Life Specialists.

While medical professionals are loving your products – what are the families saying? There has been a lot of excitement! Parents have told me that their kids are just so happy to be represented. I've been tagged in some videos on social media showing kids opening their gifts and squealing. It's very cute.

What does your daughter Josie think about what you do for work? Oh, she loves it. I'm so impressed with her because I don't take the time to explain things, but she'll take our little vitals monitor and put it on the doll and say, 'Oh, no, her heart's not good! She needs oxygen!' So then I'll get her the little oxygen set, thinking, where are you learning this stuff?

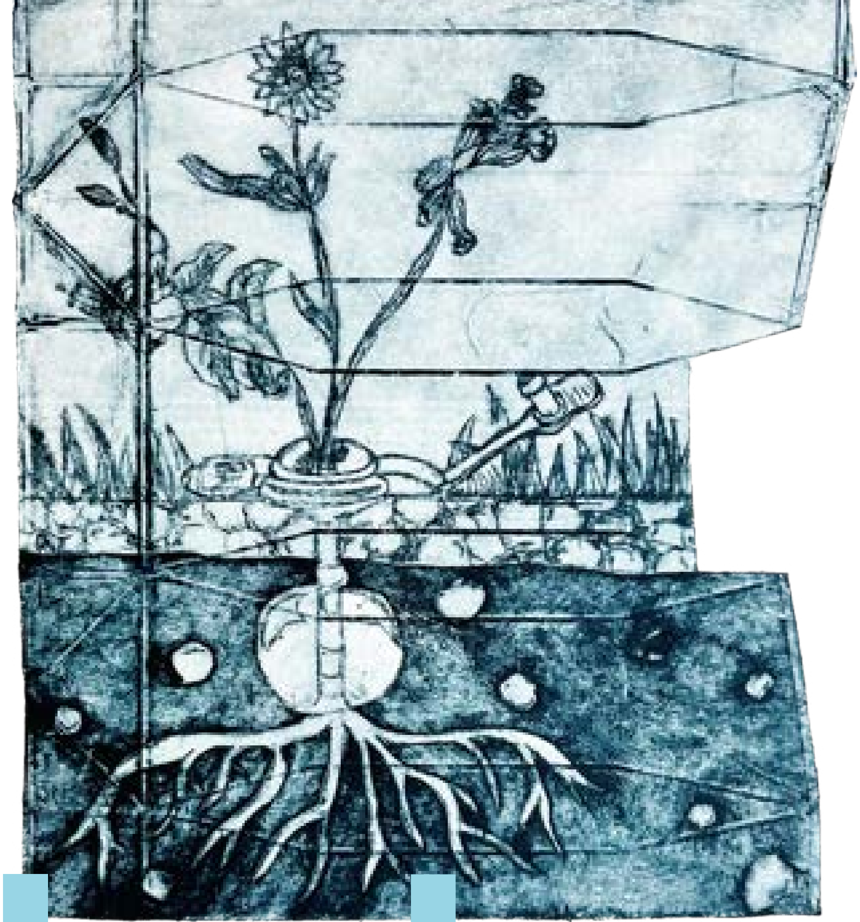
She loves everything and whenever I make a new device, she wants to play with it. She has her own collection of our products with little defects.

Do all of Josie's toys wear little medical devices? Yes, because I use her stuffed animals for my TikTok videos! I'll sew G-tubes on them and then she's like, wait, where did this come from!? I really need my own stuffed animals.

---

thebutterflypig.com
@thebutterflypig
The Butterfly Pig
@thebutterflypig

The Butterfly Pig has a special offer for *The Blend* readers. Use the code **THE BLEND** at their checkout for 15% off their entire online store.



'Underlying Growth'

Block buster

Robyn Wortel is clever about clogs. Here, the clinical education and training manager for world-leading medical device company, Avanos, shares her tips for avoiding gastrostomy feeding-tube blockages and what to do when they happen (spoiler alert: Coca-Cola is never the answer).

Artwork: Kathryn Lean

DON'T RUSH TO CRUSH

What's the most common cause of gastrostomy feeding-tube clogs? Incorrectly prepared and delivered medication. That's really the biggest issue. There are a lot of medications that are difficult to transition from an oral form to a liquid form and maintain appropriate dosage – and this is where your pharmacist needs to become your best friend.

If you do crush medications, crush them to a fine powder, disperse the powder in room-temperature water and deliver into the feeding tube – and please don't mix medications. There are pill crushing devices available from pharmacies and healthcare providers. There's also a fabulous resource called *Don't Rush to Crush*, which every pharmacist should have access to.

Some medications have what they call an 'enteric coating', and that enteric coating is intended to keep the drug intact until it transitions through the stomach. If you've got medication that needs to be absorbed further down in the gut, your pharmacist and health care team will guide you.

FLUSH, FLUSH, FLUSH

Another cause of feeding-tube blocks is not flushing properly – and also not leaving time between delivering medication, flushing, and starting feeding again. What happens inside the stomach is different to what happens outside the stomach. And when you've got a combination of food and medication in a very small, confined space like a feeding tube or extension set, chances are they're not going to get on terribly well together.

Make sure you flush with at least 15ml of water before, after and between each medication and once you've finished administering your meds. For nocturnal or continuous feeds you want to be routinely flushing your tubes with at least 30ml of water – and for bolus feeds, flush at least 60ml of water before and after meals.

WHEN YOU'VE GOT A CLOG...

First of all, never use Coca-Cola or fruit juices when you're trying to shift a feeding-tube blockage as these liquids can actually cause clogs or create adverse reactions. I would always start with room temperature water and the sooner you can get on to it, the better. Using a wide syringe – ideally 30mls or bigger – you want to start a gentle pumping action with the water. Pushing it in, pulling it out, pushing it in, pulling it out, to see if that shifts the block.

Sometimes you need to push the water into your tube and let it sit for a bit – up to 20 minutes – and then come back and start the pumping.

A smaller syringe will, of course, give you greater pressure, but you're then more likely to damage the tube. Our recommendations have always been to use a 20-30ml syringe so you even out the pressure. You want to shift the clog, not burst the tube.

If medication is the reason for your blockage, you'll probably find that only water is going to unblock it. There are enzymatic clog dissolvers, like Avanos' CLOG ZAPPER*, that can work on protein-based clogs, like those caused by formula and blenderised feeds.

IF YOU CAN'T SHIFT THE CLOG...

What's your back-up plan if your gastrostomy tube is blocked and you can't unblock it? Everyone should have a spare feeding tube so you can replace it yourself if you've been trained to do so, or rock back up to your healthcare professional, hospital or your doctor so they can change it with as little interruption to your daily life as possible.

It's traumatic when you can't feed or medicate, so it's a huge relief when you successfully unblock or replace a tube and then realise why it was blocked in the first place – and know how to avoid that happening again.

The literature* tells us that there's up to a 45 per cent chance a feeding-tube will block over its lifetime so, if yours does get clogged, you're certainly not alone. Everybody has to make a couple of mistakes along the way and it's okay to make those mistakes. But know what caused the mistake, rectify it so it doesn't happen again, and share that information. Proper information, well shared, is invaluable.

** 'Clogged Feeding Tubes: A Clinician's Thorn', Practical Gastro, Nutrition Issues in Gastroenterology, Series #127, accessed via: practicalgastro.com/2014/03/13/clogged-feeding-tubes-a-clinicians-thorn*

AVANOS

This article was made in partnership with Avanos. For easily digestible information about tube-feeding at any age and any stage, visit TubeFed by Avanos at tubefed.com.au.

When your medical team just isn't that into blends...

Registered dietitian Hilarie Geurink, the founder of Blended Tube Feeding, pushes back against common points of resistance from some doctors, therapists and dietitians around the topic of blenderised feeds.

If they're saying 'don't do this diet' Sharing your reasons for starting a blended diet, backed by research, can be quite helpful. You can even provide articles* to support your case. Ask them if they would want to receive the same formula every day, for every meal. Wouldn't they want to have some real food and be included in family meals?

If they're saying 'get the commercial formula right first' It can be very difficult to 'get it right' with commercial formula. Many people struggle with digestive issues, leading to an ongoing quest for the 'right' solution, involving lots of medications and formulas in a cycle that can take a long time to resolve. A well-tolerated plan saves time and frustration for all – a win-win situation!

If they're saying 'you won't be able to maintain or gain weight' With the right support and resources, blending meals that meet nutrition needs is entirely possible and much easier, so get that support. Plus, it's important to note that ongoing vomiting or poor formula tolerance can make weight gain really challenging.

If they're saying 'food safety is a concern' Food safety is important whether you consume food by mouth or by feeding tube. Simply follow safe food-handling practices – clean surfaces, cook and store food properly, and make sure to keep food at a safe temperature – and this will ensure your food stays safe.

If they're saying 'you'll clog your tube' With the right equipment, it's easy to avoid clogging a feeding tube. High-powered blenders work wonders, turning most foods into liquid form. And for pesky foods, a fine mesh strainer saves the day, or can be used to sieve blended meals when using a standard blender.

If they're saying 'it's too much work' Sure, it's more work than formula. But imagine all the time you'll save when you're no longer dealing with feeding intolerance! Many families I work with batch blend meals for the week, and find they spend far less time blending than they would if they were preparing meals and snacks daily for oral intake.

blendedtubefeeding.com
@blendedtubefeeding

Hilarie's step-by-step course **Blended Tube Feeding Made Simple** includes a large database of recipes and a supportive community for questions along the way.

Health Outcomes and Quality of Life Indices of Children Receiving Blenderized Feeds via Enteral Tube: ncbi.nlm.nih.gov/pmc/articles/PMC6660979/
Basics of Blenderized Tube Feeds: A Primer for Pediatric Primary Care Clinicians: ncbi.nlm.nih.gov/pmc/articles/PMC6575127/
Blenderized Tube Feeding: Health Outcomes and Review of Homemade and Commercially Prepared Products: aspenjournals.onlinelibrary.wiley.com/doi/10.1002/ncp.10493

Doctor's orders

We sit down with Dr Chris Elliot, a paediatrician working with families to manage complex issues around feeding.

Hey Chris, why are some doctors fearful or resistant when it comes to blenderised tube-feeds?
The short answer is that most doctors don't know or think much about blended feeds. They're not afraid of them, it's just that tube-feeding isn't a big part of most doctors' practice.

The longer answer is that originally all tube-feeds were blended real food. Then we had this miracle invention – commercial formula – which is stable at a range of temperatures. It's easier to transport, it's nutritionally complete, and it became very, very popular to the point where 'all tube-feeds are formula'.

Now we've come to a situation where formula doesn't work for some people and then they're stuck. Some families have shown a lot of advocacy and courage and explored blenderised feeds again, and some doctors and allied health professionals have listened to those families. The AuSPEN Consensus Statement on blended tube-feeding is a wonderful example of how this diet is being adopted by the health sector with sensible precautions.

However, put into the context of all the health issues doctors manage, blenderised tube-feeds are a subsection of tube-feeding, which is a subsection of all feeding challenges, which themselves are a subsection of all medical issues.

Most doctors just don't come across blenderised tube-feeding in their regular practice. So I think the better question is, why are doctors uncomfortable with things they don't know much about?

Okay. So why are doctors uncomfortable with things they don't know much about?
My impression is that it comes down to a perception of risk and responsibility. In a traditional illness model – epilepsy, diabetes or cancer for example – families cannot be experts in the pharmacology and physiology of their condition so the doctor takes all the responsibility for prescribing and managing medicines.

In a feeding situation it's really different. Meals happen outside the hospitals and clinics, and are prepared

“Most doctors just don’t come across blenderised tube-feeding in their regular practice. So I think the better question is, why are doctors uncomfortable with things they don’t know much about?”

and orchestrated by families. In that situation a family and their doctor have to be willing to share responsibility. The doctor’s job is to communicate the relevant medical information about what a child needs and why. The family’s job and responsibility is to feed that child safely however they want.

In my practice, I’m very happy for families to try things as long as I have communicated what I know about the risks and benefits of that approach. That way, if they want to proceed, I’m able to share responsibility for succeeding or failing with them.

Coming back to tube-feeding, shared responsibility is a much safer place for me as a doctor than if a family asks me to take full responsibility for their blenderised feeds. I can’t do that.

How can we set up a collaborative approach to blenderised tube-feeds with our care team? There are many ways. You could, for example, say to a doctor: ‘I’m really interested in blenderised tube-feeds. I understand that this is my food, my kitchen, my blender, my child, my home and that this all happens totally outside your medical office and it’s not prescribed. I’m willing to take responsibility for the food I give my child. But I would like to partner with you to help understand what medical risk there might be.’

That is very different to saying: ‘You’re my doctor. You prescribe my child medications. I want you to prescribe them blended tube-feeds and tell me what to give, how much to give, and to take responsibility for what happens if it goes wrong.’

I started medicine when I was 17 and I’m now in my 40s, so I do know a lot about it, but I’ve never tube-fed a child in the community. I’m very uncomfortable with the idea that my expertise in how to tube-feed a child in their own home would be elevated above 20, 50 or 100 families who actually do it on a daily basis.

In a medical context I would be considered an international expert on tube-feeding, but just as a doctor. I know things you need to know, you know things I need to know. We can each take responsibility for our own actions. That’s a really great basis for a safe partnership between us.

Blenderised tube-feeding is having a bit of a moment – but it’s not for everyone, is it? Blenderised tube-feeding can definitely be an option for children when it’s safe for them. I refer families and clinicians who are interested to the AuSPEN guidelines. It’s absolutely not necessary or right for all children, though. Don’t put blenderised tube-feeding on a pedestal. It’s another way of feeding your child, nothing more and nothing less.

A parent said to me once, ‘Breast, bottle, tube or spoon – fed is fed, and fed is best’. And I would add to that: ‘Blenderised tube-feeds or formula – fed is fed, and fed is best’. You have to work together with the health professionals who really know you and your child, to find a way to feed your child that suits you best.

childfeeding.org

Personal accounts.

- Maddy Reid
- Hannah Setzer
- Stephanie Kelly
- Emma Green


my tummy hurts but i'm
being really brave
about it

Making magic

Writer Kate Thomas will one day need a feeding tube, so who better to chat with than Maddy Reid, a woman hellbent on helping others love life with her NJ tube in tow.

Interview by Kate Thomas

Maddy Reid has listened to the Harry Potter audiobooks over 1000 times, which explains why she named her nasojejunal (NJ) tube 'Tubius Hagrid'.

Tubius Hagrid has been part of Maddy's life since early 2023. Prior to this, she was diagnosed with gastroparesis, a condition making it hard for her stomach to digest food.

As a curious tubie-to-be myself, I sat down with Maddy to discuss what it's like to live with a feeding tube, some of the surprising challenges, and the magic of 'glimmers'.

Here are a few of the gems she shared:

'It's okay not to feel great'

Having a feeding tube has been life-changing for me. I was in such a dark place physically, which impacted my mental health hugely as well. I gaslit myself into thinking that my condition shouldn't be affecting my mental health as much as it was.

I don't know one person with a chronic illness who hasn't been affected by mental health [challenges]. We believe we're being overdramatic for being anxious or depressed because of what's happening in our lives. I think people might see me and think, 'oh, she's happy', but I still really struggle. But it's okay to not feel great.

Chronic illness can completely change your entire life. It upended mine. I was unable to work and have only recently started trying to work a few hours. It's hard to apply for jobs where you want a three or four-hour shift, maybe twice a week.

It's important to acknowledge that your chronic illness is affecting your mental health and to have people on board who will check in. >>

'The magic of social media… and glimmers' In 2020, when I was getting my first feeding tube, I found an Instagram post about tube-feeding. I remember feeling so alone at the time and then realised that I wasn't. That's the magic of social media. In a weird way, it's nice to know that other people are experiencing what you are experiencing, even though you don't want anyone else to experience it.

That's when I realised that I wanted to be able to bring some light and positivity to tube-feeding. Not to take away from the reality of what people experience, but I just realised that it's so easy to get bogged down in your own negativity or in the negativity of the world. So I created my social media account @paralysedwithlove, to bring some love that still exists through all the negativity and sadness.

I like to get a little glimmer, even when everything can seem so grim. You might be stuck in hospital, but you had a really nice nurse. That's the glimmer and it can be all you need for that day to keep you moving through. And I think that's the sort of stuff that I want to be able to bring.

'You don't realise how much of life is literally waiting for the next meal' There were so many little things to learn when I first got my feeding tube. Including how much food plays a part in our lives. It's everything! Even at the cinemas, everyone around you is eating delicious popcorn.

As I've gotten closer to being nil-by-mouth, it's been a lot harder. Isolation comes with not being able to eat the same as you might have previously. Going out to a café with friends is no longer the same. You feel separated on a social level.

Every now and again I get a real boost and want to cook for my family or look up recipes for people that I know they'll enjoy. My love language is still to create for people and, when I focus on that, it doesn't bother me as much.

'The saying "your body knows best" is so true' If you are questioning yourself about whether you need to seek a second opinion, think about what you would tell your best friend. Chances are you probably should.

You want to have a team of medical professionals that you completely trust and feel like you can be upfront with. You want to be able to say to them, 'I ate a whole packet of chips, I know that I shouldn't have, but I did'.

I think that's been huge for me, having professionals around me who have my back. I'm very lucky and I know for some people it can take years. I've had doctors who have dismissed me, told me that I wasn't sick. I remember thinking I was wrong, that they're the doctor, they've trained and are a specialist. But I had to trust myself and my instinct to look for another doctor.

> "I like to get a little glimmer, even when everything can seem so grim."

I ended up finding a fabulous specialist who, in my first appointment, said 'I think you need a tube'.

At that point I was overweight and he didn't even question that. He was on the money straight away, it was so validating. The saying 'your body knows best' is so true.

'I'm never embarrassed when a stranger asks what my tube is'
Since getting my feeding tube, the biggest change for me has been the mental clarity that I've gained.

I didn't realise how foggy my mind was before. I'm reading again. I think I've read 67 books this year since getting the nasojejunal tube. I can catch up with my friends and be more active in our conversations. I've also accepted a part-time university offer for next year, started moving my body and exercising – lightly – and so much more. And I can work on my mental health more than I've been able to in almost four years.

Life is still hard and I'm still not where I want to be, but there are so many positives that Tubius has brought me and I'm so, so grateful.

Because of all of this I'm never embarrassed when a stranger asks what my tube is or ashamed when I need to have some extra help with things. I just can't see how I could be ashamed of something that has done so much for me and my life.

@paralysedwithlove

If this article has raised concerns for you, please contact Beyond Blue by phone or online at beyondblue.org.au

Fit for purpose

In Powhatan County, Virginia, you'll find Hannah Setzer. Probably doing deadlifts, running after her four teenagers or tending to her menagerie of animals and mini farm, quite possibly while tube-feeding. This memoirist, disability advocate and life coach muses on food, family and how she inadvertently influences the fitness space.

How did tube-feeding first come into your life? I was born with a medical condition of cystic hygroma – it's now called lymphatic malformation. This means there are cysts in my head and my neck, so pretty soon after I was born I had a tracheostomy and a gastrostomy (G) tube placed.

I can swallow little amounts of water but not any food. I've never eaten any other way. I have a gravity bag that's hanging on a door jamb right now. I'm feeding as we talk.

So you're a lifelong tubie – and for most of your life you were on a commercial formula. How did you find your way to blending real food? I was on PediaSure until I turned 18 and then I was put on Ensure – which is just PediaSure for adults – and was on that until I was about 24. At this time I had friends who were really into health and nature and hippy stuff. They'd been seeing a chiropractor and were like, 'he's holistic, he's amazing!'

So I went to this chiropractor and he said 'why are you on Ensure? I'm going to get you off it'. He's a chiropractor – he's not a dietitian, nutritionist, or anything like that. But he said, 'okay, you're going to get almond milk and protein powder, and that's what you're going to live off'. And I was like, 'okay, great!'

Almond milk and protein powder don't have a lot of calories so I lost 20 pounds in like two weeks. I also felt terrible.

I bet you did. Eating just almond milk and protein powder is pretty nuts. I really should have sued that chiropractor for malpractice. But the friends who recommended him to me said, 'okay, we'll figure this out'. We started mixing in bananas and applesauce and spinach – stuff that would blend up easily.

While this was going on my parents were super mad at me. I was like a skeleton, so they were not happy. But I kept thinking, we can figure it out. Just let me keep trying.

> **"I didn't know anyone else with a feeding tube. I definitely didn't know anyone else that was blending their own food. I was on my own, but I was like, I'm going to get this right."**

On the Ensure and the PediaSure I was sick pretty much all of the time. At least once a month the cysts in my face would get infected. I know now that this was because of all the sugar in those formulas. Cysts thrive on sugar.

Even though I lost a lot of weight as I was trying out real food, I wasn't sick. I could feel that there was something to this. Just let me keep trying!

Around that same time I sold everything I owned and I moved to South America, to Brazil. And in Brazil they eat a lot of beans and rice. So I ate a lot of beans and rice – blended and strained – and those are high-calorie foods, so I started to gain weight. I was in Brazil for eight months and was only sick once.

This was before Instagram had really taken off. I didn't know anyone else with a feeding tube. I definitely didn't know anyone else that was blending their own food. I was on my own, but I was like, I'm going to get this right.

That was eight years ago now and I'm still on blended food. I'm also healthy and active. And I attribute it all to that chiropractor who was probably reckless and almost killed me!

You're very nice to credit him with starting your blenderised food journey. What does your diet look like now? There are foods that I eat every day. I do raw eggs – which I know people have a lot of feelings about, but I've never gotten sick – and then there's olive oil, peanut butter, Greek yoghurt and cottage cheese. Every day this stuff is going in, along with whatever leftovers we've got. >>

Yes, I've heard you describe yourself as the human garbage disposal in your house! I have four teenagers and they made my food yesterday. I have no idea what they put in it, but I was in a staff meeting today and I burped, and it smelled and tasted awful. I had to apologise to everyone. I think they put kimchi or something that was fermented in it, because I stink!

You're very trusting, especially of teenage boys. After today, maybe not.

While we're on the topic of bodily grossness, your stoma does not behave itself, does it? It's horrible. It's so crazy because my trach [tracheostomy] is perfect, it has never had any issues. But my G-tube is always leaking.

How do you manage it? I just try to keep my stoma clean and dry. I use a piece of gauze that I change quite often throughout the day. Every time I do laundry there's gauze everywhere because I leave it in my pockets, and my husband is like, 'stop it!'

I also use a lot of diaper rash creams, which is kind of gross but I think what happens is similar to diaper rash. Stomach acid leaks out, it hurts and it breaks down the skin. So me and Desitin diaper rash cream are friends.

Are there ever times when you feel ripped off that you don't get to chew and swallow food? No, I think I have it good. I feel sorry for people who have to sit down at a table and eat. I just hook it up and keep on doing whatever I'm doing.

The convenience is awesome – especially for someone who's doing as much as you do. When did fitness become a focus? I've always been somewhat athletic and in college I started running and doing half marathons. Then in 2018, I had a New Year's resolution to work out for 30 days, just to see what it would be like. I did all kinds of things, like running, rock climbing, a spin class or yoga videos at home. Thirty days came and went and I loved it. Then I was like, maybe I'll go for 50 days. And then 100 days. Maybe I could do a whole year.

Somewhere in there my mindset shifted from working out to being intentional with my body and moving it however felt good that day. And it started just becoming something that I craved.

In August 2018 I started my Instagram account, which used to be called Feeding Tube Fitness, because my friends were like, 'we're tired of listening to you talk about fitness. Can you talk about it on the internet, not to us?'

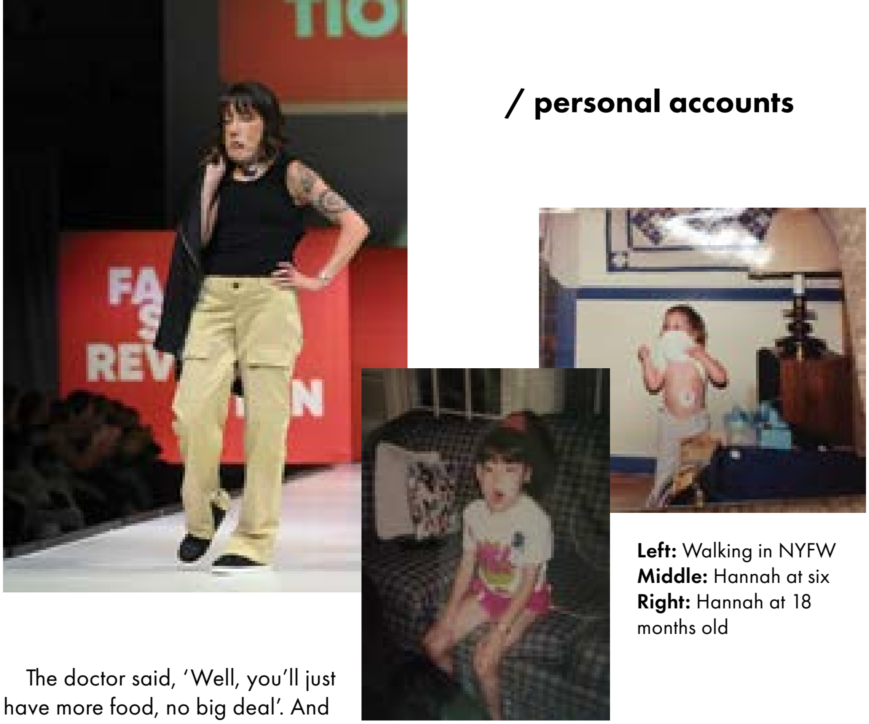
That you did. And your account, now called @hannahvsetzer, has over 100k followers very keen to hear you talking about fitness. Back when you got started, was there much disability representation happening in the #fitspo realm? Honestly, aside from the Special Olympics, I didn't really know anything about the accessible fitness community. I didn't know about adaptive athletes, but I got connected to some really cool ones pretty quickly on Instagram. Especially now that I do CrossFit competitively, I've realised there are a lot of really badass disabled athletes in the world.

That said, the fitness industry is significantly behind in including disabled people. And I was like, I'm going to change this. I'm going to make fitness accessible to all people! Which I don't think I've done, but I definitely advocate for inclusion and representation everywhere and anywhere.

> **"The fitness industry is significantly behind in including disabled people. And I was like, I'm going to change this."**

How do people tend to respond to the content you put out there? They're overwhelmingly positive. But it's really easy for people to be like, 'oh my gosh, you're so inspirational!' I'm a disabled person who's working out, which is nothing special. But because people don't see it very often, they're like, 'This is amazing!'

Sometimes I have people in my community respond to these comments, saying, 'she's not inspirational. Yes, this is cool, but it would be cool if anyone did it, right?' Then, on the other side, there are idiots who go, 'you're not doing that right'. And it's like, okay, but you're not doing anything besides insulting people on the internet.



Left: Walking in NYFW
Middle: Hannah at six
Right: Hannah at 18 months old

NYFW Image courtesy of Getty Images

It's a very judgy space – perhaps no more so than in the area of online dating. You and your husband, Brandon, met on Tinder in 2016. What's it like to date with a feeding tube? I think I'm way more confident now than I was back then. If I was dating now I would be in a bikini, feeding tube out. I would not give a fuck!

And to be honest, I would say my face is a lot more to take in than my feeding tube. That was a natural deterrent for people, which was good, because I didn't have to deal with idiot boys. I knew that if somebody swiped left, clearly they were capable of seeing past my face, so that was nice. I think I told Brandon about my feeding tube in our first conversation.

Nowadays, the question is, can Brandon change your G-tube? No, he would never! He's fine with it but he does not want to participate at all. One time, I had my feed hanging up in the kitchen on a cabinet and he accidentally stepped on it and ripped my tube right out of me. He was like, 'Hannah! Oh my God!' And I was like, dude, it's okay!

We were foster parents at the time and one of our sons – who was 13 or so – went and got me a new feeding tube and a towel. He could handle it, while Brandon was still like, 'Argh!'

You guys were foster parents and now you're adoptive parents to four teenage boys. Why did you decide to have this kind of family? I did a lot of genetic testing just to see what would happen if we ever did get pregnant, to see if any of my stuff was genetic, and it wasn't. We also saw a doctor at my gynaecologist's office, just to talk about, okay, what would this look like? What happens with my feeding tube if I get pregnant?

The doctor said, 'Well, you'll just have more food, no big deal'. And I was like, no, there's a hole in my stomach, what happens to that when my stomach gets bigger? And the doctor said, 'I don't know'.

That kind of sealed the deal for us. Okay, not a thing that we're doing. But we knew that there were kids who needed homes and we had a home that we were willing to be open with.

The goal with foster kids is for them to go home to their families. However, we were asked if we would adopt our first son – the one who helped me with my feeding tube after Brandon accidentally ripped it out. He had a little brother that was in another foster home, so we adopted them both. Then we got a call around Christmas time in 2020 about two more brothers that need to be adopted. So here we are with four teenage boys who we never anticipated adopting!

Beyond your own family, you're hoping to support other kids by building a local inclusive playground. How's that going? We have the land, but it's a slow process. It's also a $2 million project – and we don't have $2 million! But it'll happen someday.

How did it feel to walk in New York Fashion Week 2023 – and do you think there'll come a day when we see feeding tubes showing up regularly on fashion runways? It was amazing to walk in NYFW and see such representation on the runway and in fashion. I hope there is a day, soon, where feeding tubes and all their glory will be displayed in magazines, on the runway, in TV shows, and in displays in stores.

All of this work you're doing is raising awareness. When it comes to tube-feeding, what do you wish more people knew? I wish people knew the freedom you can have with it. People think tube-feeding is like a death sentence when it's the opposite. You can live and you can thrive and, if you want, you can run half marathons.

@hannahvsetzer
@hannahvaughnsetzer

Tubie of influence

This viral sensation is showing the world what tube-feeding really looks like. In her case, a newlywed health professional who won't sacrifice fun, friends and the hope of a future family.

Stephanie Kelly has told everyone – specifically, a half-million-strong social media following – precisely how often she does a poo. This information is of interest because, unlike your stock-standard stomach, Steph's doesn't digest food.

'Do I still poop? The answer is yes,' says the 28-year-old Sydneysider in one of her videos, addressing a common question from her TikTok audience.

As a nurse, she can tell us with authority that 'poop' is not only made up of food waste, but also secretions made by our organs, such as bile and mucus. 'It's not much, but I still do go,' she says. 'Probably about once a fortnight.'

In spreading awareness of life with chronic conditions and feeding tubes, Steph doesn't shy from sharing such details. Millions of people are intimately acquainted with her nightly bedtime routine – Steph's most popular video to date – where she methodically prepares her overnight total parenteral nutrition (TPN), intravenous (IV) fluids and jejunostomy (J) tube feed.

Her 'how-tos' range from maintaining a relationship while frequently unwell to fake-tanning with an IV central line. She often reviews her hospital meals (favouring porridge, macaroni cheese and mashed potato) and once told the tale of how her poodle, Oatley, bolted at a cat while tangled in her TPN tubes.

Often confined to a hospital bed, surrounded by fairy lights, Starbucks-laden friends and Lego builds, her sweetness and sincerity shine through the direst of scenarios. In June of last year she married her long-term partner, Adam, in a beautiful celebration before a months' long stay in hospital, where she needed several blood transfusions.

Always teaching and staunchly optimistic, Steph takes her devoted followers through every high and low. Here, she reflects on her tube-feeding journey – and how it has led her to the role of 'accidental' advocate. >>

Steph, can you tell us why, on TikTok in particular, there's an astonishing amount of tube-feeding content being shared? I think a lot of people on TikTok started doing their 'get ready for bed and set up my tube-feeding stuff with me' videos. And you've got cystic fibrosis patients with feeding tubes, you've got eating disorder recovery girls and boys, you've got people with my conditions. It's beautiful to see that we are all connected by feeding tubes – to see that there's a person on the other side of the world that's going through exactly what I'm going through.

It's also really lovely for others to see and I love educating. People think they know what someone with feeding tubes looks like, but we don't have a 'look'. TikTok shows people that so many of us go home and set up our tube-feeds and you'd never know.

Tube-feeding has been a big part of your life. When did you start? I first had a feeding tube when I was a teenager. I have Ehlers-Danlos syndrome (EDS) and postural orthostatic tachycardia syndrome (POTS), along with heart conditions including supraventricular tachycardia and atrial fibrillation. As a child my blood pressure would drop and my heart rate would go up. I would pass out, I would lose control of things. It was very unpredictable and random. I also had a potassium-wasting channelopathy, which is so rare.

> **"It's beautiful to see that we are all connected by feeding tubes – to see that there's a person on the other side of the world that's going through exactly what I'm going through."**

In 2010 I temporarily lost my ability to swallow – I had dysphagia – so I needed a nasogastric (NG) feeding tube for a few weeks. That was my first experience of tube-feeding and I wouldn't say it was a negative one. I had the discomfort of getting it put in, but once I got used to it, it was easy.

Then I had no troubles at all for a while. I went through life, did my nursing degree – which was a big thing, because I just didn't think that I could do that, especially with how debilitating my POTS and EDS was – and then I worked for four years at The Children's Hospital at Westmead, which was where I pretty much grew up. That was really, really fulfilling. I loved being back there, treating children with feeding tubes.

And then one night after work, in March 2018, Adam and I had a car accident. At the time, I thought I was just dealing with shoulder, rib cage and neck injuries, and only expected to be off work for a few months. But I also had a nerve injury. My neck was really bad and I had to have surgery on both shoulders. So a year went by.

At what point did you realise that eating was an issue? I've always had a really bad stomach and would randomly vomit. Because of my EDS, my stomach has always been mildly delayed in emptying, which would explain the occasional flare of vomiting, but this got a lot worse a year after the accident. I was losing so much weight that my gastroenterologist recommended we put in a nasojejunal (NJ) tube to try and keep my weight up. So that was my first experience with an NJ. >>

At that point, I hadn't joined any support groups. I don't know if I just couldn't find it, but I couldn't see any community of people who had tubes and were advocating. I just thought, 'Oh my God, I'm a 23-year-old with an NJ'. Because I had only worked with children who had feeding tubes – and had one myself when I was younger – I thought it was a very childlike thing to have. And my condition just got worse and worse.

I was vomiting up the NJ because even though my feeds were going to my intestine, my stomach still couldn't empty itself. So I had an NG and an NJ, and I think that was probably the lowest point, mentally, because I didn't really know how to process what was happening to me. I hadn't seen anyone else with these tubes and I felt like I'd lost my independence. At that point I couldn't eat, I couldn't go out with friends. I felt very isolated.

I had those tubes for six to nine months and then my medical team said, 'This is looking like a long-term thing. Your stomach is paralysed, so we're going to put in long-term tubes'. First I had a gastrostomy-jejunostomy (GJ) tube and I didn't mind that, but unfortunately, the J portion kept coming up and flipping. So then they said, we'll put in the two – the G and the J – and that's where I'm still at. I still have both and, honestly, they have given me so much life and freedom.

I want to rewind a bit there and ask, how did you feel, after overcoming numerous challenges and scoring your dream job, to dramatically regress health-wise?

Looking back, it was a bit of a blur. I remember a lot of people were like, 'I just can't believe this has happened to you'. And I don't think I actually even – I'm going to use the word digest, which is funny, because I don't digest – but I couldn't actually digest what was happening, or sit with it, for a really long time. I was so traumatised and saddened by the experience that I don't think I processed the emotions until a year or two later.

Not until I got some stability with my tube feeding and had the long-term tubes put in did I actually go into therapy, because I thought I was fine.

I had started to withdraw socially, I didn't want to hang out with friends. And the therapist asked, 'Why is that?' I was like, well, I don't really have much to talk about. I'm not doing anything. And she said, 'Do you feel like you have nothing to talk about because you're not working?' And then I was like, oh my gosh, I've lost my dream job that I worked so hard to get.

> **"Now that I'm back working as a nurse – at the moment, in a special care nursery – I feel like I've found a whole new purpose."**

There was so much grieving that I did after the accident, but it wasn't until that moment that I realised I was processing that grief.

At that point, I was told I would probably never work again. And if we'd had this conversation two years ago, I would have been a total mess. But now that I'm back working as a nurse – at the moment, in a special care nursery – I feel like I've found a whole new purpose.

Nowadays, what does eating and tube-feeding look like for you?

I wake up in the morning and I'll disconnect my overnight tube-feeds, which run at a slow rate and are called 'trickle feeds'. Because I now get most of my nutrition through TPN, the trickle feeds are just there to remind my intestines that food still has to go through, because your stomach and intestines are a muscle – and if you don't use it, you lose it.

I don't have much of an appetite until later in the day because my stomach, essentially, doesn't work. I get a couple of my medications through my J tube and the rest goes intravenously. My next medications are at midday, so wherever I go – even if I'm at work – I carry my little MIC-KEY connector and a syringe with my medication. Then I have more medications at about four or five in the afternoon, and then again before bed. I'm always disconnecting and reconnecting.

I have both a G dangler tube and a MIC-KEY button. My dangler is for drainage, so everything I eat orally needs to go out of that, because if it goes through, I get really bad pain and obstructions. I drain two or three times a day. If I eat at say, 1pm, then I'll drain at around 4 or 5pm, but the timing differs based on the richness of the food. If it's bland, it can stay there longer. If it's hot chips, it can stay there all day. But if it's butter chicken, it's got to come out within an hour or two because otherwise I get really unwell.

I've had my draining tube for a few years now, and while there are risks associated with it – similar to excessive vomiting – thankfully I've had no issues. It's been life-changing because I can go out and eat with friends. And even if it's a rich meal that I can't tolerate, my friends all know about it and I can just go and drain in the toilet.

It's hard to judge what my stomach

will do, so sometimes my husband and I will be on our way home from a meal and have to stop in at McDonald's so I can go to the bathroom and drain.

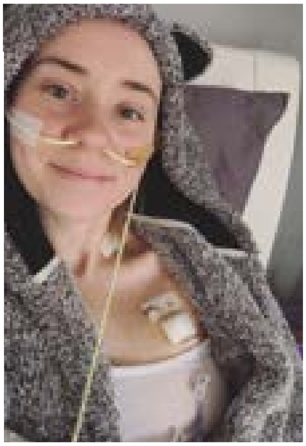
If you'd told me five years ago that this would be my life, I would have been like, 'Whoa, that's too much to handle. What do you mean I have to drain every time I eat?' But having the perspective of, well, if you don't do that, you can't eat at all, I'd much rather this life. I have that freedom – and not everyone does. Everyone's feeding-tube journey and conditions are very different. But yeah, it's wild.

Getting the breadth and diversity of tube-feeding out there is so important – and you're doing this through both modelling and content creation. When did this part of your working life kick off?
I've always secretly loved *Australia's Next Top Model*, but never in my wildest dreams did I ever think I'd be modelling. And then one time when I was admitted at RPA [Royal Prince Alfred Hospital], I found my beautiful friend, Maddie. She was documenting her cancer journey on Instagram, and I was like, 'I'm in the same hospital!'

When you find another young person in an adult's hospital, it's like you've struck gold. You're like, oh my gosh, you know exactly what I'm going through. All their friends are out on a Friday night as well, while you're in hospital, missing out. No one else really gets it.

Maddie invited me to an event run by Cancer Chicks, a charity co-founded by my now good friend Ricki, who went through her own battle with cancer and found that there was nothing for young women. No connecting, no groups or stuff like that. So she made her own gorgeous charity.

At the time, when Maddie invited me to come to a Cancer Chicks event, I said, 'Well, I don't have cancer, so I don't think I can.' And Maddie said, 'You know what? Suffering is suffering. >>



You've got a central line, you're having surgeries, you're in hospital all the time. It's the same.' So I went along to a Pilates class with these girls and they were gorgeous.

I've found that in a lot of online support groups, people can get really caught up in the negative side of their illness. Unfortunately, that consumes them. What I loved about this group was that all these girls, whether they'd been in remission for a decade or had just started their journey, were like, 'I've got this going on, but I'm also dancing every week and I have work' – there was just this lust for life. And I value that in support groups, because sometimes we can get really caught up in the negative parts of our stories.

So I joined Cancer Chicks and we opened up the group for 'Chronic Chicks' and branched out. At one of our retreats we were doing a photo shoot and we were all showing our scars. And I was like, well, I've got feeding tubes, so let's take photos of them. One of the board members said to me, 'You should be doing this more often' and connected me with someone they knew at Australian Fashion Week.

Just a few months later, I was walking in the Future of Fashion show. News outlets contacted me and wrote about me as the 'Aussie nurse with feeding tubes', which was great, because young people with feeding tubes, feeling different from their peers, could now see this model just like them on a catwalk.

That was in May 2022 and since then, you've amassed a colossal social following. How did this happen? I started sharing content at the end of that year and in just six months had almost 100,000 followers on TikTok, so it grew so quickly. I'm with an agency now and I'm starting to get clothes and things sent to me. My agency asked me, 'What are your goals?' And I said, 'This was a little bit of an accident'. I didn't actually mean to make this almost a career. But now that I have, I'm going with it, because I think there could be really big changes made. One of my videos has 20 million views, and so many people have seen tubes now and they know of TPN.

Looking ahead, what are you excited about – both professionally and personally? I'm really excited about working with more brands, because who says that people with disabilities and with feeding tubes aren't consumers? We consume! I mean, to be honest, I think I consume more than the average person because I'm stuck in hospital with nothing else to do. We are the target market that no one realises is there. So yeah, that's my goal professionally.

Adam and I are also planning on having a family. A popular question I get on TikTok is, can you fall pregnant? And yeah, it's happening, don't worry! I've seen a fertility specialist and a high-risk obstetrician and now that I'm at a healthy weight, my reproductive system is all good to go. So I'm very excited to show that whole stage of my life.

In one of your social media captions you wrote that it took you a long time to accept your body with its scars and tubes. How do you feel about your body now? I wouldn't lie and say that I'm 100 per cent happy with my body. I think it would take a long, long time to get to that point – just in general, tubes or no tubes. It took a while to learn to love a body that was already a bit damaged, and then had been in an accident and got more damaged. You can feel like your body has kind of betrayed you.

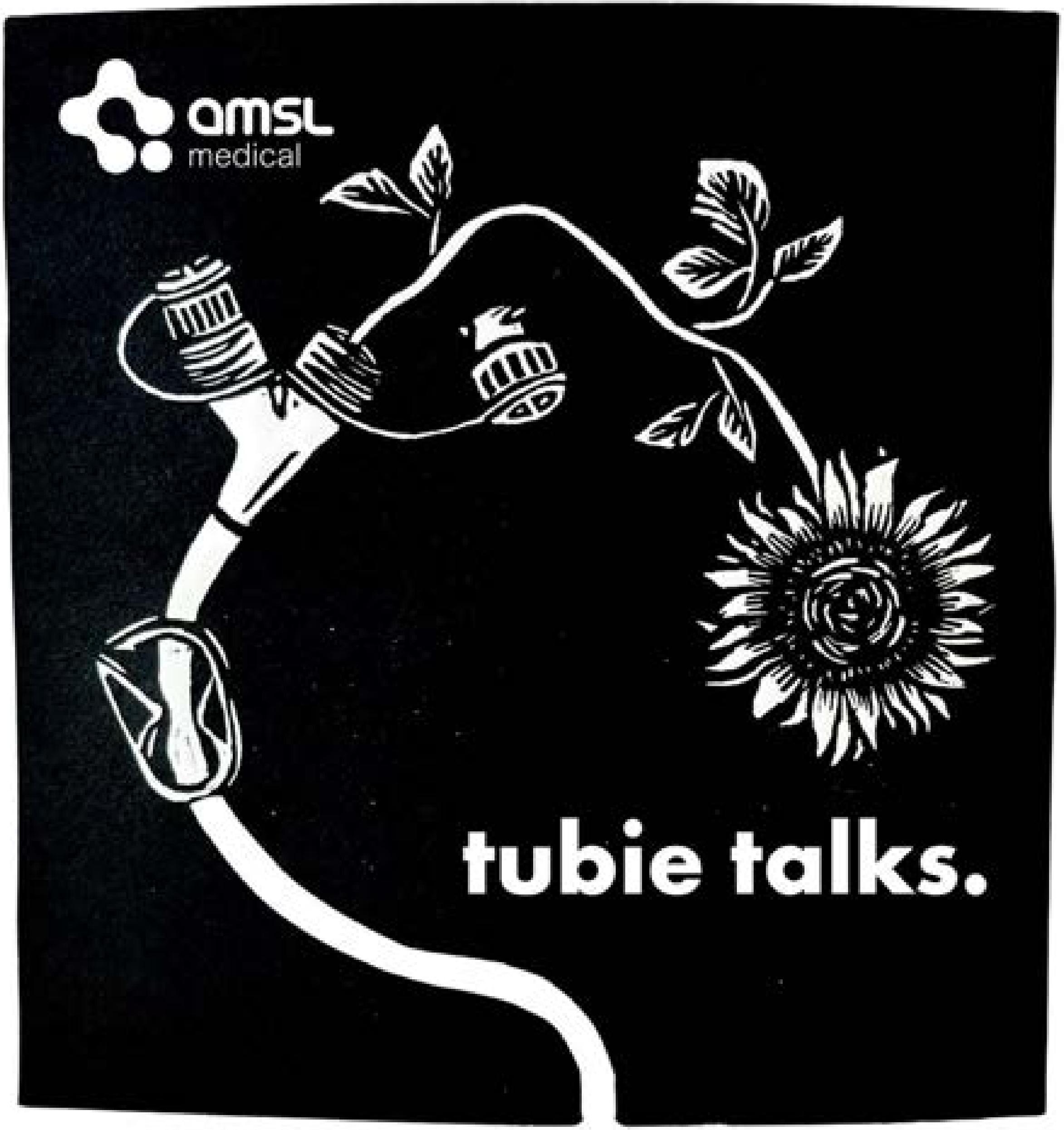
Then with the tubes, I kept getting infections, so I was really frustrated. I just felt like I had this constant smell and that got in the way of intimacy and wanting to go out. My tubes were making me very insecure. I would say it took a good year of looking at myself in the mirror every day before a shower and thinking, 'If I didn't have these tubes, I wouldn't be here'.

I think that perspective is so important. Feeding tubes are not the enemy. If they get infected or blocked, or if I need surgery, those tubes are not the enemy. They are the reason why I'm still here and the reason why I've now become an influencer, which has given me this whole different outlook on life. And I'm grateful for it.

@stephkkelly

@stephkkelly

Hear more from Steph on the new Tubie Talks podcast, wherever you like to listen to your pods.



Artwork: Kathryn Lean

A series celebrating the lives of people and families who tube-feed.

Tune in on your favourite podcasts platform.

Have feeding-tube, will travel

Emma Green is the ultimate globetrotter. Since she was a newborn, she's been camping, road-tripping, cruising and long-haul flying – tube-feeding all the way. Before jetting off again, this time to Tokyo, Emma tells us some of her travel tales.

As Muhammad Ali said: 'Impossible is just a big word thrown around by small men who find it easier to live in the world they've been given than to explore the power they have to change it. Impossible is not a fact. It's an opinion. Impossible is not a declaration. It's a dare. Impossible is potential. Impossible is temporary. Impossible is nothing.'

Travelling when you need a blended diet or are tube-fed is not impossible. You just have to be ready to problem solve.

Of the 25 countries I've visited, my top five travel destinations are England (London and New Forest), Tasmania, Italy (Rome), Austria (Vienna – I love *The Sound of Music*) and Ontario (Waterloo). I never travel without a list of my friends and a spare button. My network is important.

Sometimes on the plane people are curious about my pump or bolus feeds, but I don't remember anyone openly staring when I've travelled – not at how I eat, anyway.

The strangest thing I've eaten while travelling was snails on a cruise when I was still eating orally. I've also tasted crickets. Now if I want to eat local cuisine, I look at it and smell it before it's blended.

I'm going to Tokyo soon. We have already bought the NutriBullet Baby Bullet Blender to take for blending meals and have found some pre-made pouches for adults on pureed diets that are available in chemists there.

In Vienna and Rome, I had to have pureed baby food in jars and we didn't know what it was, so we had to go by the picture on the jar.

Tube-feeding can be a great way to make new friends. It was very hot at a conference in Toronto and I was having a mango slushie via my tube in a hallway. A mum and her daughter stopped because they were surprised that I was having something so cold. We became best friends and they travelled to Australia to stay with us and we then travelled to Ontario for a white Christmas with them!


Alboraya
Real Monasterio de la Trinidad
59
23
Plaza Ávila
Pintor Vilar
Viveros Municipale
NW
W
N
NO
SW
S
O
OS

A mini-break with Emma's mum, Toni-Anne Green

What gave you the confidence to camp and travel with Emma as a baby and young child? I never saw disability as a reason to not let Emma explore her world. We camped from very early on, first in a tent, then a camper trailer and then a caravan. Small kids are pretty portable. We always had powered sites and comfy beds because no one manages well on a poor night's sleep. It wasn't without challenges but that made it fun – especially when we could look back and laugh at our strategies for managing inaccessible bathrooms!

We began travelling internationally when Emma was around 10, with her first cruise, and then with long-haul flights from age 12. When I could, I pre-arranged delivery of some of the items Emma needed. We weren't doing a blended diet back then as a full-time choice. Emma chose to do that later.

Have you ever run into tricky situations around tube-feeding while travelling? Heathrow Airport comes to mind. I was forced to open and taste each of the baby food pouches I had for Emma in my carry-on luggage to prove they weren't dangerous goods. The biggest challenges have usually been things like blocked tubes or buttons. We learnt over time that we just needed to bring extra in case this happens, even if we ended up carting it all home again.

What are your top tips and tools for travelling with a loved one who tube-feeds? Be adventurous but take precautions. We usually have Milton tablets and zip-lock bags for sterilising on the go. We don't take risks with water quality – if in doubt, use bottled water. We always take stoma ointment, like Kenacomb, and a bunch of button pads. We usually have broad-spectrum antibiotics with us, too, and a replacement button.

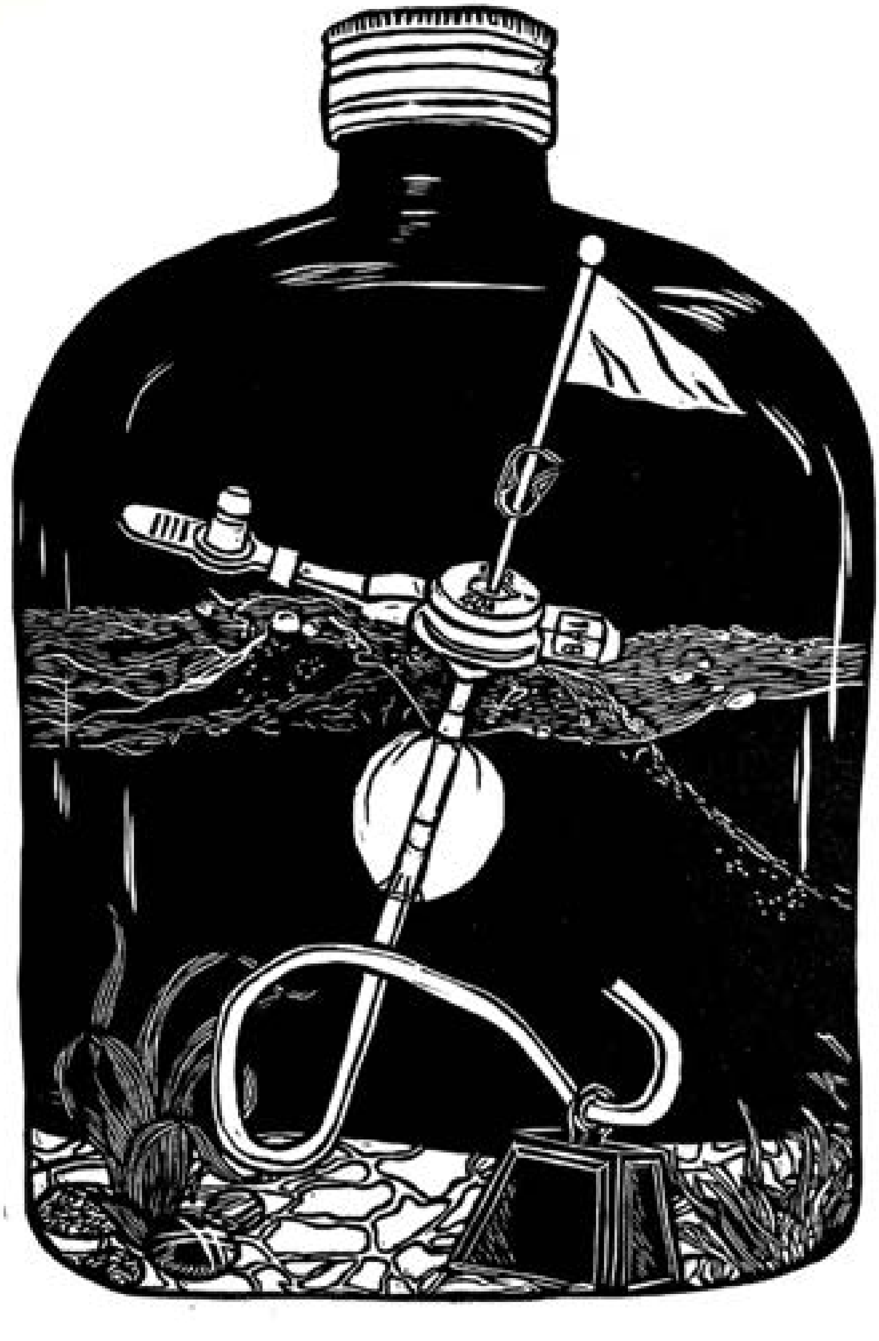
The reality is, things happen. You can only prepare so much and if you do run into a hiccup, reach out to the online feeding-tube community. Someone will always try to help.

What words of advice do you have for families who are new to the tube-feeding space, perhaps feeling like their travelling days are over? What's the old adage about it never being over? I have friends who have travelled long-haul with family members on continuous feeds and oxygen. It doesn't have to be impossible, you can usually make it work.

It's never going to be as simple as the pre-tube-feeding days – or pre-kid days – when we could just pack on a whim and travel. The key is now in the planning and preparation.

Some of our trips had two years of planning, reaching out by email to suppliers in the countries we planned to visit, reaching out to our networks in those places, contacting accommodation to ensure there was a fridge and a blender. Even taking our own blender – yes, we've done that too!

When you see your son or daughter light up because they're holding the ticket to their favourite city – Emma's is London – it really makes the extra planning worthwhile.



Like what you see?

Find original artworks and prints from Kathryn Lean at kathrynlean.com


GNDA

On the road

The Travelling Tubie Project's Chloe Turner has spent the past two years caravanning around Australia with her family, including her young son, Lincoln, who tube feeds. Having recently welcomed a third child to their brood, the Turners are gearing up to take another lap. Here, Chloe shares her advice.

When travelling with someone who tube-feeds, the biggest thing is planning but not overthinking it. You don't need to have everything planned to a tee, just have your emergency plan sorted. For us, it was being trained to replace Lincoln's tube, having his emergency meds, knowing where hospitals were along the way and having a backup pump which, for us, was just having big syringes.

Paperwork is also a big thing because while you're travelling, if you need to see doctors, they will question you, like: 'Are you seriously travelling with a kid that has medical needs?' So have some letters from your paediatrician, ENT, dietitian, speech therapist, whoever. Having a good comeback is useful, too – 'I can put this tube back in, we've got a good protocol, we can call his doctors at any time' – then they don't freak out as much.

Questions from medical professionals can make you doubt what you're doing, but we've gone all the way around Australia and Lincoln is now the healthiest he's ever been. It's the best thing we've ever done.

You don't need the fancy travel stuff. We went for a comfortable caravan because we sold our house before we left, so we wanted a house on wheels. But we've met so many families that are doing it with just tents and campers with pop-tops. They're still absolutely living the dream.

We have run out of tube-feeding supplies while travelling, so I'm thankful that our Facebook tubie community is amazing. In each state there's generally a medical family page. We put a post up and within minutes had people asking, 'what's your address?' and posting me stuff.

My best advice is don't be afraid. We're about to head off again and my anxiety is back up, but I know that once we start moving, it all just washes away. Once you take that step, it will be okay. There's always a way to make it work and you get very inventive. Just do it and the rest will work out.

"We've gone all the way around Australia and Lincoln is now the healthiest he's ever been. It's the best thing we've ever done."

Flying high

A trio of tube-feeding families share their international travel stories and tips.

STACEY PHILLIPS, Brisbane, Australia

We started preparing for our trip to the US well in advance because we knew it was going to be a bit of a mission. I saw my GP every week for two months, getting letters to justify our medications and making sure we had all of our supplies sorted.

I was quite prepared to be questioned because I had all of our medication in my carry-on bag. When you've got three kids all on meds, it's full on! Normally our chemist makes Webster-packs for us, but we had to go back to the bottles and everything needed to be labelled.

We ended up booking an extra bag just for all of my tube-feeding son, Callum's, supplies. We took three weeks' worth of Wholesome Blends pouches, vitamins, a spare G-tube button, spare extension sets and syringes.

We didn't have any problems tube-feeding on the plane. We just asked the airline staff for a cup of water so we could do Callum's flushes and used a ChooMee SoftSip Food Pouch Top with our pouches of food for his bolus feeds.

Callum ate about half of his meals via his G-tube while we travelled – often because there are no vegetables in America! We found a new love of The Cheesecake Factory because it served real food. Otherwise it was just chips or pancakes from IHOP [International House of Pancakes].

When we went to Disneyland, the only tricky things were finding a seat and making sure we had enough water. You don't want to be lining up for food and drink, so we ended up hiring a locker and grabbing supplies from there as we needed.

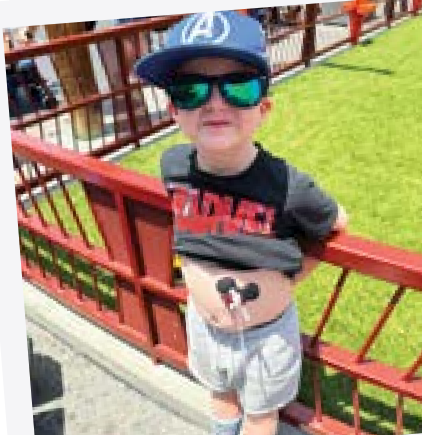
We also had a Disneyland disability access pass so we could 'virtually queue' for rides and attractions, which was awesome, because lining up with three kids with ADHD is hard work!

As we were leaving the US, security staff stopped us and checked Callum's thickener and his water bottle, but as soon as I said he needed these things for medical purposes, they sent us on our way. All of those weeks spent getting those letters and I didn't need them once! But I bet if I hadn't had them, they'd have wanted them.

While we were in the US, people really didn't take much notice of Callum's tube-feeding. It wasn't out of the norm and no one really questioned us. It was just so inclusive – I've never experienced anything like it.

Travel checklist:

- ✓ **Book an extra bag for supplies**
- ✓ **Stock up on shelf-stable feeds**
- ✓ **Get disability access passes at theme parks**



JENNY AND NEIL ANDERSON, Victoria, Australia

We've got a son, daughter-in-law and grandson who live in the UK and we've travelled to visit them three times since my husband, Neil, had a stroke. He was 60 years old when it happened and, since then, he's had a G-tube.

Once Neil started tube-feeding, when it came to travel, I think the biggest issue for me was that I was really scared about how I would feed him. But I thought, you know what? I'm not going to let this beat us. We're in this together and we either do it or we don't. And we made that pact that we could do this.

Our dietitian helped us by suggesting we take powdered formula for the plane, because you're not allowed to take any liquids more than 100ml onboard. So I could mix that up on the plane, but then my concern was, where can I get Neil's formula once we're in the UK?

When we first went over I took a whole lot with me. But then my daughter-in-law and I did a bit of research and found a local place that supplied it, so I got some delivered to their home. I've decided that from now on when we go, I'm just going to order it over there.

> "To those who are new to travelling with a feeding tube, I say go for it. Be positive, stay strong, you can do it."

We do gravity feeds on the plane and Neil can hold the syringe for me while we're pushing it through. We also get assistance throughout the whole journey, which takes the worry out of navigating airports. The only thing that's a bit embarrassing is that while Neil is pushed in a wheelchair, I have to sit in the airport buggy. We have a good laugh!

I always have Neil's G-tube button changed about two weeks before we go, because then I can make sure that there are no infections or problems with it. To those who are new to travelling with a feeding tube, I say go for it. Be positive, stay strong, you can do it.

Travel checklist:

✓ Explore the option of powdered formulas
✓ See if you can source feeds locally
✓ Ask your airline for assistance throughout your journey

SARAH THOMAS, Brisbane, Australia

I took my then-10-year-old twin sons, Cohan and Lewis – Lewis has a G-tube – to Tokyo and this meant two flights with a stop in Singapore. We had to be prepared for 15 hours of tube-feeding in transit and I had to charge Lewis' feeding pump during our stopover so it would make the distance.

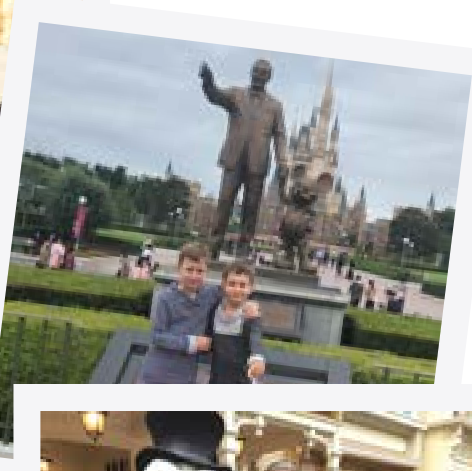
I had a whole suitcase of formula and pouches of puréed baby food for Lewis, because this was before I started making Wholesome Blends. That was one of the defining moments of – this is ridiculous, we need a better option!

I had got all my doctors' certificates and letters for our medications organised, but then a few days before we left, I realised I had to fill out a form that was in Japanese. After months of planning, I didn't have the time or energy to find a translator to help me do this. So I sent a message to my girlfriend who we'd be staying with in Tokyo, saying: 'See you soon! And by the way, if for any reason I get arrested, can you just come get the kids from the airport?'

We got to Tokyo and as we made our way through customs with my bag of medical supplies, I said to Lewis, just lift up your shirt and show them your tummy. This got us through, no issues. Our chemist had specially labelled our medications and that was really handy. With hindsight, I'd probably get a letter translated explaining what we were doing and why we were bringing stuff into the country.

While it wasn't ideal to bring baby food over for Lewis, I'm glad I did, because I couldn't understand the Japanese food labelling. My friend there showed me what looked like a juice popper, telling me it was actually full of saké – Japanese rice wine – and that she'd nearly put it in her kids' lunchboxes!

If you're travelling with a tubie, the best thing you can have is a connection to the local tube-feeding community because they'll never let you down. It doesn't matter where you are in the world, you can almost guarantee that the tubie community will help you if you are in trouble.



Travel checklist:

- ✓ Have a letter translated into the local language
- ✓ Ask your chemist to label medications as required
- ✓ Link in with the local tube-feeding community

An expert approach to travelling with a feeding tube

With Natalie Gentile, clinical nurse consultant and registered stomal therapist at Children's Nursing Queensland.

TRAVEL SAFE

Make sure that your insurance is right and up to date. We've heard that for some people with stomas, insurances need to change. So making sure your travel insurance encompasses your tube-feeding needs is really important.

PACK RIGHT

Practically speaking, feeds are heavy and can be difficult to travel with. You might be able to arrange to have some formulas waiting for you at your destination, but often families are going to have to pack all of their formulas. So making sure that you've got the right kind of baggage allowance is really important.

I would also always pack a spare device. It doesn't happen often, but in recent months, we've had families tell us that their gastrostomies burst soon after flying. This doesn't seem to be consistent with any particular brand or type of G-tube button, it just seems to be what people are saying. So having a spare device is really important.

TRAIN UP

If a family isn't trained in how to reinsert a feeding tube, it might be worth learning how to do this before they go on holiday. If a tubie has a well-established tract – and we would say that's over six months old – most of the time it's fine to do a change yourself. And that's a really important skill that families can learn.

Feeding pumps might be important to take with you, but for a lot of people, if you're in a bind, you can gravity or syringe feed. Have a chat with your medical team about what a troubleshooting plan looks like if your feeding pump goes out of action.

TRAVEL DOCS

G-tube buttons and other devices are packaged with a little implant device card. It's really important that people take this along with them, because you might seek medical support while travelling, whip your shirt up and find that a medical professional has never seen your particular device. This could also be helpful while you're going through customs at airports.

Also make sure you've got a supporting letter from your GP, your nurse, your stomal therapist or whoever it needs to be, explaining what kind of feeding tube you have and how it works.

BON VOYAGE!

While we're always available to help with any issues experienced abroad, we don't often hear from the tube-feeding families we treat while they're travelling – and I take that as a good sign. It means things are going well. Like most families, they want to travel and experience new things. They just have to make sure that they've done that bit of planning beforehand.

AVANOS

This travel feature was made in partnership with Avanos. For easily digestible information about tube-feeding at any age and any stage, visit TubeFed by Avanos at tubefed.com.au.

Read us online:

the blend.

a mix of stories, advice and recipes for tubie newbies

issue 3

theblendmag.com

Please note: Nutritional analysis is expressed as per full batch of recipe and is a guide only.

Energy distribution (kcal/ml) is a guide only and the total volume of each batch will vary depending on the type of blender used, cooking methods and the type of ingredients used.

Recipes

- Breakfast blend
- Omelette with kale
- Fresh summer blend
- Thai-inspired peanut quinoa salad
- Chicken fettuccine Alfredo
- Chocolate smoothie

Our blended recipes section is
brought to you by Blendtec Australia

blendtecaustralia.com.au blendtec_australia Blendtec Australia


blendtec
blendtec

Breakfast blend

By registered dietitian and founder of Tube Dietitian, Lina Breik

Ingredients

- **1 cup cooked oatmeal**
- **1 cup of milk (can be plant-based)**
- **1 scrambled egg**
- **½ cup kiwi fruit**
- **½ cup banana***

Method

1. Combine all ingredients in a blender and blitz thoroughly until smooth.
2. Strain out any lumps with a sieve.

*Bananas do tend to oxidise and turn brown when exposed to air, which can affect their taste and appearance. Therefore, recipes containing bananas are generally best consumed immediately rather than stored for an extended period.

Nutrition

- **Total volume: 700mL**
- **0.9kcal/ml**
- **Fat: 23g**
- **Protein: 31g**
- **Carbohydrate: 67g**
- **Fibre: 6g**
- **Sodium: 270mg**
- **Iron: 3mg**

tubedietitian.com
@TubeDietitian


blendtec
blendtec

Omelette with kale

From Line Pedersen and registered dietitian Pia Overgaard Bjørn, co-founders of Bellyfood

Ingredients

- **2 slices of white bread, chopped**
- **1 boiled egg**
- **¾ cup of kale, chopped**
- **⅓ cup of green beans, chopped**
- **¼ cup mushrooms, sliced**
- **2 teaspoons of olive oil**
- **1 cup of oat milk**

Method

1. Blanch any frozen vegetables and boil the egg.
2. Put all the ingredients in your blender and blend until there are no lumps.
3. Strain the meal into a bowl.
4. Lightly tap the bowl on the countertop to remove air bubbles.
5. Pour the food into suitable containers or eat right away.

Nutrition

- **Total volume: 500mL**
- **0.85kcal/ml**
- **Fat: 20g**
- **Protein: 18g**
- **Carbohydrate: 38g**
- **Fibre: 9g**
- **Sodium: 410mg**
- **Iron: 3.9mg**

Find more blended diet recipes from Line and Pia at bellyfood.dk

@bellyfood.dk
Bellyfood


blendtec
blendtec

Fresh summer blend

By Claire Kariya, clinical dietitian at Natural Tube Feeding Inc

Ingredients

- **1 cup thawed frozen peas**
- **2 tablespoons whole-milk ricotta cheese (substitute firm tofu for vegan/dairy free)**
- **1 tablespoon olive oil**
- **2 teaspoons lemon juice**
- **1 teaspoon lemon zest**
- **1 teaspoon chopped fresh dill**
- **½ cup steamed potatoes**
- **¾ cup vegetable broth**

Method

1. Blend all ingredients together until smooth.
2. If you want a thinner texture, add a little more broth.
3. Strain as needed and enjoy!

Nutrition

- **Total volume: 400mL**
- **1kcal/ml**
- **Fat: 18g**
- **Protein: 14g**
- **Carbohydrate: 40g**
- **Fibre: 10g**
- **Sodium: 600mg**
- **Iron: 3.2mg**

Find more recipes from Claire Kariya in The Original Natural Tube Feeding Recipe Book

naturaltubefeeding.com
@naturaltubefeeding
Natural Tube Feeding

Thai-inspired peanut quinoa salad

From registered dietitian and Blended Tube Feeding founder, Hilarie Geurink

Ingredients

- **½ cup quinoa, cooked**
- **¼ cup red cabbage**
- **¼ cup shredded carrots**
- **¼ cup peanut butter**
- **1 tablespoon maple syrup**
- **1 tablespoon ginger root**
- **1 tablespoon soy sauce**
- **½ tablespoon ground turmeric**
- **¾ cup water or broth**

Method

1. Prepare and measure out all ingredients.
2. Add to the blender and blend on high for ~2 minutes, or until completely liquified and with no chunks.
3. You may need to strain the blended meal if there are any lumps.

Note: If you need to change the consistency, you can add more or less liquid. Keep in mind that blended food tends to thicken over time, particularly if it contains starches. Please note that adjusting the amount of fluid will also modify the nutrition information provided.

Nutrition

- **Total volume: 400mL**
- **1.5kcal/ml**
- **Fat: 35g**
- **Protein: 21g**
- **Carbohydrate: 46g**
- **Fibre: 8g**
- **Sodium: 470mg**
- **Iron: 3.2mg**

Find more recipes from Hilarie in her Blended Tube Feeding Recipe Book

blendedtubefeeding.com

@blendedtubefeeding


blendtec

Chicken fettuccine Alfredo

From paediatric gastroenterology dietitian, Kate Dehlsen

Ingredients

- **1 cup risoni pasta**
- **400ml thickened cream (can use coconut cream as an alternative)**
- **1 clove garlic**
- **100g butter (can use Nuttelex as an alternative)**
- **80g parmesan cheese (or dairy-free cheese)**
- **500g chicken thigh fillets, chopped into large chunks**
- **2 tablespoons oil**
- **300g broccoli, cut into small florets**
- **200g cauliflower, cut into small florets**
- **½ can evaporated milk (or evaporated coconut milk)**

Method

1. Cook pasta in salted boiling water until just underdone (not quite cooked). Add in vegetables and cook for another 2-3 minutes until pasta is al dente. Drain and save 500mL pasta water.
2. In a frypan, cook chicken in oil until just cooked through.
3. In a saucepan, heat cream until hot, then add butter and crushed garlic clove. Stir until butter is melted. Add in parmesan cheese. Simmer over moderate heat for 5 minutes to thicken the sauce slightly.
4. Add chicken, pasta, vegetables and 500mL of pasta water to sauce and stir through. Add in ½ can of evaporated milk.
5. Cool, add to blender and puree. If too thick, add in remaining evaporated milk.

Nutrition

- **Total volume: 2400mL**
- **2kcal/mL**
- **Fat: 330g**
- **Protein: 170g**
- **Carbohydrate: 120g**
- **Fibre: 17g**
- **Sodium: 2200mg**
- **Iron: 10mg**


blendtec

Chocolate smoothie

From the founder of Wholesome Blends, Sarah Thomas

Ingredients

- **60g baby spinach, raw, loose (2 loosely packed cups)**
- **80g avocado**
- **100g cucumber, unpeeled**
- **75g strawberries, fresh or frozen**
- **1 large egg (50g), hard-boiled, shelled**
- **250ml full-fat milk**
- **30g chocolate-flavoured protein powder**
- **2.5 tablespoons smooth peanut butter**
- **3 tablespoons cocoa powder**
- **1 tablespoon avocado oil**
- **40g dry rolled oats**

Method

1. Combine all ingredients and blend until smooth.
2. Immediately pour the blend into individual serves and refrigerate. Freeze portions that won't be consumed within 48 hours.

Nutrition

- **Total volume: 750mL**
- **1.5kcal/ml**
- **Fat: 67g**
- **Protein: 56g**
- **Carbohydrate: 58g**
- **Fibre: 27g**
- **Sodium: 515mg**
- **Iron: 15mg**

Find more recipes from Sarah in her book Wholesome Blends: Blending Recipes for Love, Sharing Stories for Life

wholesomeblends.com.au
@wholesomeblendsau
Wholesome Blends

What tubies want

A directory of go-to products and online communities.

Tubie Fun

We are an Australian owned and operated, award-winning family business celebrating a different way of feeding. Through walking the same journey with our tube-feeding child, we know first-hand the highs, lows and everything in between that this lifestyle brings. It's our mission to provide the tube-feeding community with a wide range of handmade, high-quality products that are both fun and functional. We want you to help children and adults who tube-feed feel confident and express their personalities – all while normalising this wonderful way of feeding.

tubiefun.com.au
@tubiefunau
@tubiefun

FreeArm Tube Feeding Assistant

Misti and Will Staley created a 'helping hand' for tube-feeding their son, Freeman. The FreeArm holds gravity syringe feeds and pump feeds to make eating at home, hospital or on-the-go a breeze. The FreeArm folds up easily to fit in your suitcase, comes in four fun colours and is NDIS purchasable through AMSL Medical, Surgical House, Tubie Fun and more.

freearmcare.com
@freearm.tube.feeding.assistant
@FreeArm

Boon Grass Drying Rack

This widely used and loved bottle drying rack just happens to work a treat for syringes and other bits of tube-feeding kit. You can buy the Boon Grass Drying Rack from several retailers. Helpful hack: Dry your syringes tip-down on this one.

Wonsie

Wonsie specialises in larger-sized cotton bodysuits for kids and adults. We are committed to providing quality, practical clothing solutions for people with a variety of needs and have a bodysuit range which is designed specifically to assist easy tube-feeding access. Our range also includes adaptive swimwear, incontinence aids and bedding protection. Our goal is to provide products which give peace of mind and help make daily life a little easier for all families. We offer worldwide shipping and are registered NDIS providers.

wonsie.com.au
@wonsie
@wonsiekids

Whole Enteral

Enrich is a nutritionally formulated meal replacement and the debut product of WHOLE Enteral, the business baby of tubie mum Ali Howell and speech pathologist Dr Emily Lively. Nut, dairy, gluten, soy and GMO-free, Enrich is made from plant-based wholefoods and meets the Australian Food Standard for Formulated Meal Replacement.

whole.net.au
@whole_en
@WHOLE.en

Real Food Blends

Real Food Blends is America's only ready-to-feed, 100 per cent real-food option for people with feeding tubes. Enjoy nutritional variety with six different meals and one snack made with real protein sources, fruits, vegetables, whole grains and fat sources. Each pouch is made of five to eight ingredients, that's it! Available in the US only.

realfoodblends.com
@realfoodblends
realfoodblends
@RealFoodBlends

Sinchies

Sinchies reusable pouches are frequently used as an enteral feeding bag to allow people of all ages who have a disability or oral aversion to ingest the nutrients required to keep them alive and healthy. Our products can also be used for a blended diet and are suitable for G-tubes and Nutricia Infinity feeding pumps. Sinchies pouches are small, compact and light, making it easier and more comfortable to be out and about for tube feeders.

sinchies.com.au
@sinchies
@Sinchies

A Simple Patch

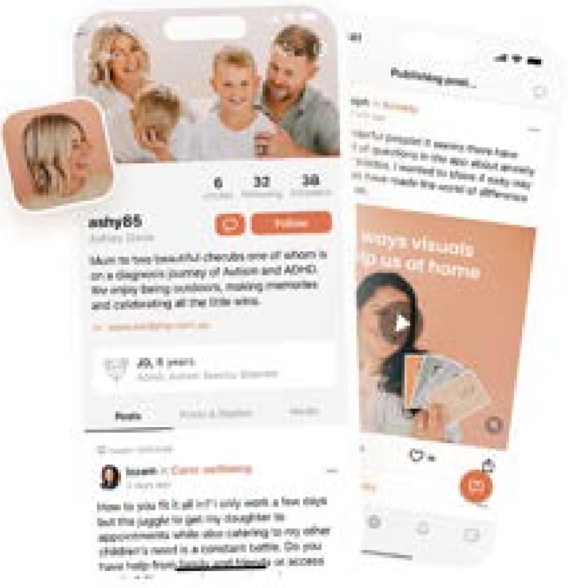
Megan Wassink's daughter uses medical devices and tubes and Megan wanted to make them look less medical. Enter A Simple Patch, an online store selling fun and strong-sticking printed medical tape in a range of prints or, if you like, a custom design of your own choosing.

asimplepatch.com
@asimplepatch
@asimplepatch

Wholesome Blends

Wholesome Blends is Australia's leading blended whole-food option for tube-fed children and adults. Our nutritious, all-natural and high-calorie meals are shelf stable – which means no refrigeration is required while storing. They're also free of dairy, soy, nuts, eggs and GMOs, free of added sugars, free of preservatives and additives, and made with love by a tube-feeding family, for tube-feeding families. With four varieties to choose from, Wholesome Blends is making it easy and convenient for families to benefit from a blended, whole-food diet.

wholesomeblends.com.au
@wholesomeblendsau
@wholesomeblend



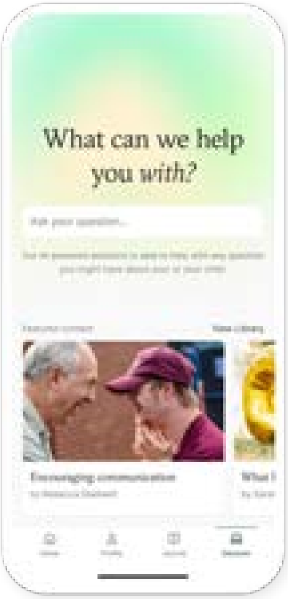
Hibi

Hibi is a new app designed to help families manage their child's care. The app includes tools to store, track and share care information, alongside access to expert content for families navigating their child's care.

hibi.health

@hibihealth

Hibi



Kindship

We're Kindship, a community of parents helping each other navigate childhood disability and the NDIS. Our parenting journey isn't covered in (most) parenting books. And let's face it, Googling and getting a 'professional opinion' can feel like a minefield. That's where we come in. On our free (yep, free!) mobile app you'll find circles of conversation on topics important to you, mentorship from parents with a deep understanding of the NDIS, and a safe space to be unapologetically yourself.

kindship.com.au

@kindshipapp

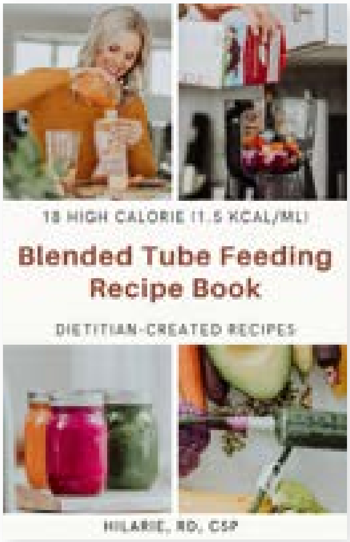
Kindship

Blended Tube Feeding Recipe Book

If you're new to blenderised tube-feeding and aren't sure where to start, this ebook is for you! Inside this offering from Hilarie Geurink you'll find 18 dietitian-created, high-calorie recipes with directions for how to easily swap out your formula for these nutritious, blended meals. You'll also find lots of helpful advice on how to prepare, store and consume the blended meals.

blendedtubefeeding.com

@blendedtubefeeding



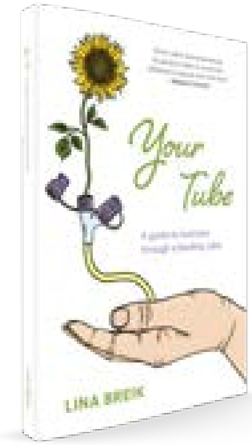
Online Communities

- **childfeeding.org**
- **ausee.org**
- **feedingtubeawareness.org**
- **tubefed.com.au**
- **BlenderizedRN Facebook group**
- **Feeding Tube Australia Facebook group**

Your Tube

This comprehensive book from dietitian Lina Breik adopts a reader-friendly approach by demystifying nutrition jargon and presenting tube-feeding in an accessible manner. Its goal is to bridge the gap between you and your feeding tube, empowering you to understand and discuss your nutritional needs effectively with your care team.

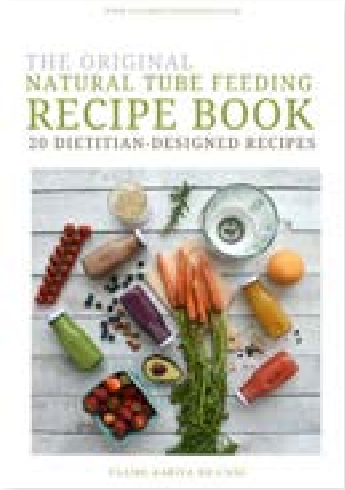
tubedietitian.com
TubeDietitian



Easy Follow Easy Swallow: Transitioning off a PEG tube back to oral eating

This recipe book is the work of trained chef and head and neck cancer survivor Yvonne McClaren, who you can meet in Issue One of *The Blend*.

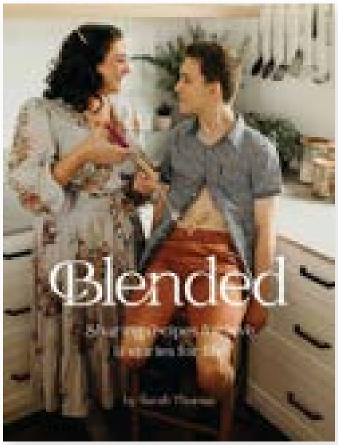
yvonnemcclaren.com
@yvonnegracemcclaren
@nofeedingtubes



The Original Natural Tube Feeding Recipe Book

Dietitian Claire Kariya shares 20 tried-and-tested blended meal recipes, each with their own nutritional information, in this photo-filled, downloadable ebook.

naturaltubefeeding.com
@naturaltubefeeding
@naturaltubefeeding



Blended: Sharing recipes for love and stories for life

Created by Sarah Thomas, the founder of Australia's beloved Wholesome Blends products, this new blended-meals cookbook is a celebration of family, flavour, and health. From Sarah's personal favourites to expert contributions from dietitians, chefs, and family recipes, discover the joy of home blending with tips, tricks, and heartwarming family stories.

wholesomeblends.com.au
@wholesomeblendsau
@wholesomeblend

Gimme five

We ask this fun-loving crew what advice they wish they could give themselves at the start of their tube-feeding journey.

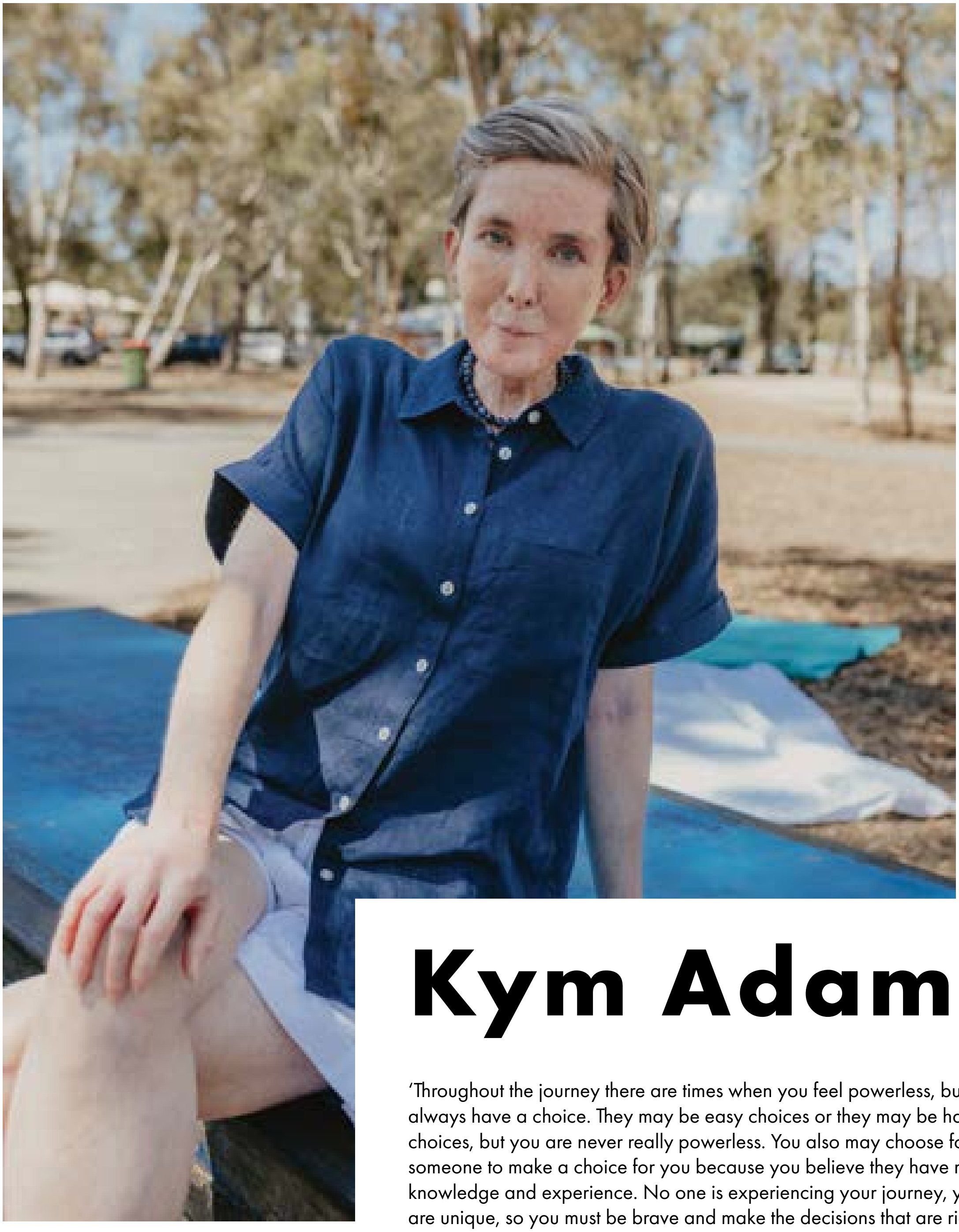
Photography by Debi Brett for Tubie Fun

Lewis' mum, Sarah

'I wish someone had picked up on my feeling that I had failed so badly as a mother, because I couldn't feed my son. This was massive and I still have grief around that to this day. I wish that someone on Lewis' medical team had been kind enough to say, "Hey, this isn't your fault, and this isn't the end of the world. This is just your new normal, you can adapt and it can be fun and happy".'

Rylee’s mum, Amie

‘If I could go back in time to when Rylee first started tube-feeding, I wish I could tell myself that it wasn’t the end of our feeding journey – that in two years my little girl would be healthier than ever with very minimal hospital admissions. I wish I could tell myself that I would be far less stressed and know my baby is getting all the nutrients she needs.’



Kym Adams

‘Throughout the journey there are times when you feel powerless, but you always have a choice. They may be easy choices or they may be hard choices, but you are never really powerless. You also may choose for someone to make a choice for you because you believe they have more knowledge and experience. No one is experiencing your journey, you are unique, so you must be brave and make the decisions that are right for you, because you are the one that experiences the consequences.’

Callum

‘Don’t listen to what other people might say about you having a tube – or think that it’s weird. It’s okay, because you don’t have to taste all the medicines you get. Also, never forget the clamp on the extension or else there will be a big mess to clean up.’

Callum’s mum, Stacey

‘Know that you are never alone! Although the journey might be tough, emotional and isolating to begin with, there is a community out there ready to wrap their arms around you and walk with you.’

Pedro Relvas

'What helped me at the start was realising that I needed to accept my reality. No situation will ever be as bad as our negative response to it. I can choose to either be the master of my journey or the victim of my journey, and I choose the former.'

Debi Brett Photography

***The Blend* magazine is an independent publication**

Founder and editor
Melanie Dimmitt
melaniedimmitt.com.au

Creative director
Edie Swan
edieswan.com

Digital director
Ash Ball
thesepeoplewho.com

Published by
Printcraft Pty Ltd

Legal stuff

theblendmag.com

Image: Debi Brett Photography