

#LettersToYoungerMe

in support of the Roald Dahl Nurses Appeal



www.roaddahlcharity.org/donate



Roald Dahl's Marvellous Children's Charity

We are appealing for donations to help establish more vital Roald Dahl Transition Specialist Nurses to support more young people across the UK.

In support of our appeal, a star-studded host of celebrities and industry professionals, who are themselves living with a lifelong health condition or disability, have written a letter to their younger selves to share the advice and supportive words they would give to themselves.

We hope you will find our collection of 'Letters To Younger Me' inspiring.

We provide specialist nurses and support for seriously ill children. Our network of 82 Roald Dahl Specialist Nurses support over 21,000 children and young people with complex lifelong conditions including sickle cell anaemia, epilepsy, rare diseases and neuromuscular conditions.

My Roald Dahl Transition Specialist Nurse, Giselle has helped me come to terms with becoming an adult and sees me as a person, not just my condition.

Ben (25)

I firmly believe that every NHS Trust in the UK should have a Roald Dahl Transition Specialist Nurse. Without this role, I firmly believe my son's health would have been negatively impacted

Virginia, mum to Ben (who has Sickle Cell Disease) was supported by Roald Dahl Specialist Transition Nurse, Giselle as he moved from child to adult services

Transition

It's a funny old thing, isn't it – and on the face of it, it looks like it will be straight forward.

Go to sleep a child, wake up a young adult. After all, what difference can a few hours make? Apart from maybe now as an adult you can be more independent.

But we all know it's trickier than that, especially if you have the additional complexity of being under the care of doctors and nurses.

Roald Dahl Transition Specialist Nurses are there to support children and young people as they move from children's to adult services. They help navigate the different clinics, different departments, new faces and the piles of new paperwork associated with moving from one service to another. They are the familiar smiling faces who understand the complexities of all the different health and social care systems and who champion us each step of the way, pick us up when we are feeling down and cheer us on.

There are more than 80 Roald Dahl Specialist Nurses based within the NHS in England, Scotland, Wales and Northern Ireland.

We know that a smooth and safe transition means young people will have better health outcomes, and that parents, carers and families will be supported too. It's one less thing to worry about at a time where there are so many changes.

That's why we are fundraising to establish more Roald Dahl Specialist Nurses in the NHS to help young people and their families make a safe transition.

This is not just a growing-up book. This collection of inspirational stories is a reminder that things will change, that lives will change. You are not alone and we have it within our grasp to make a difference.

Rosie Jones, Comedian



**Those are the qualities that make you, you.
Be proud of them, because they make
you stand out from the crowd.**

With her infectious laugh and high energy, Rosie Jones has quickly become a must-see act on the UK comedy circuit. The ex-television researcher was awarded second place in the Leicester Mercury's *New Comedian Of The Year Award 2018* and has gone on to star on *Live At The Apollo*, *The Jonathan Ross Show*, *8 Out Of 10 Cats*, *8 Out Of 10 Cats Does Countdown*, *The Last Leg*, *Rosie Jones Tries To Help*, *Live From The Comedy Store*, *Joe Lycett's Got Your Back*, *Comedy Central UK's Roast Battle*, *Mock The Week* and *Hypothetical*.

Dear Rosie,

It's me, Rosie, the older and (questionably) wiser version of you. You'll never guess what... they've found a cure for Cerebral Palsy...you're able-bodied!! JOKES, you're still disabled, but, as ever, you wouldn't have it any other way.

You're expecting me to tell you something deep and profound but, honestly, just keep on doing you.

Most importantly, keep on telling jokes, because one day you will make a living from 'em!

If I could give you one teeny piece of advice though, I'd say, never apologise. Naturally, you will do things that you should say sorry for, but I mean the bigger stuff; never

apologise for being you. You're loud, you're annoying, you're goofy, you're disabled and (spoiler alert) you're gay.

These are not new things, you're already aware of them, but sometimes you hide them because of what other people might think. Stop it. Those are the qualities that make you, you. Be proud of them, because they make you stand out from the crowd. Life is too short to spend time worrying about what other people think of you.

That's all for now,

Old Rosie xx

P.S. Stop wearing bodycon dresses.

Buy dungarees. You look great in dungarees.



www.roalddahlcharity.org/donate

Kelly is a model, mother of two and activist. A dedicated and passionate advocate for diversity in fashion and motherhood with the aim to dismiss societies preconceptions about disability and the beauty ideal. Kelly is listed in the Power 100 – a celebration of Britain’s most influential disabled people and is devoted to motivating future generations to embrace their uniqueness and be body confident. Over the course of her career Kelly has spread her message of diversity and drive internationally, across various cultures and social movements. From billboards, TV, editorials, campaigns, catwalks, panel talks and a TEDx under her belt – Kelly is a true pioneer of her field.

Dear My Younger Self,

YOU ARE BEAUTIFUL.

I want you to know you are perfect, exactly how you are.

Your body does look different – but it is something to feel proud of, not to feel ashamed, shy or embarrassed about.

Every single person on this Earth is unique as a snowflake.

So celebrate your individuality with self love, grace, confidence, peace, purpose and acceptance. Know that you don’t have to feel brave all the time.

There is so much beauty and empowerment in vulnerability – the soft, gentle, sensitive, loving nature of your soul. Do not let the world harden you.

Allow your true light to cascade through every crack, imperfection and flaw – your shine will ignite the flame in others, like stars in the night sky.

One day you will realise why you were born this way.

Love you always.

Kelly

Kelly Knox, Model



Allow your true light to cascade through every crack, imperfection and flaw - your shine will ignite the flame in others, like stars in the night sky.

Kare Adenegan, Paralympian



Photo: Nike London

**The future may seem scary
but it really is bright.**

Kare took up wheelchair racing in 2012 and was inspired to take up athletics after watching the 2012 Paralympic Games in London. "I didn't really know a lot about wheelchair racing – I'd heard of it before, but I didn't really understand how it all worked. After watching people like (British wheelchair racers) David Weir and Hannah Cockroft compete, that's when I realised that it was actually a sport out there." She set a world record in the T34 100m in 2018, and won the 2018 BBC Young Sports Personality of the Year award.

To my younger self,

Keep going and don't give up. I know it's quite lonely being the only wheelchair user at school, but it gets better. Surround yourself with kind people including others with disabilities and know that you're not alone.

Although you hate physio and all the painful contraptions that are tied to your legs, it's important that you persevere as it will increase your independence when you get older. I know you'll be surprised by this, but you will learn to love physio and stretches.

The future may seem scary but it really is bright. Don't let anyone discourage you academically as well as physically because you'll end up at your dream university studying your favourite subject, so believe in yourself and don't doubt your ability.

Keep active and enjoy sport. Being active will help your cerebral palsy and make you stronger and fitter. I know you don't think sport is for you because you are often excluded from sporting activities but don't let this put you off.

You can and will achieve in sport if you have fun and are patient.

Lastly and most importantly, take each day as it comes, tomorrow has its own concerns so focus on today, try not to fret, everything's going to be okay.

Kare Adenegan



www.roalddahlcharity.org/donate

Amy graduated from the Royal Conservatoire of Scotland in 2015. Recent theatre credits include: *Coriolanus*, *The Hypochondriak* and *13*, (Royal Conservatoire of Scotland); *Wendy Hoose*, (Birds of Paradise Theatre Company); and *Random Accomplice*, *Skeleton Wumman*, *Play, Pie and a Pint*, *Blood Wedding*, *Graeae Redefining Juliet*, (Barbican). Amy currently plays Courtney Campbell on Channel 4 soap *Hollyoaks*.

To me,

When I tell you what your life is now in your 30s, you won't believe me. You know that woman that told you you'd never go to drama school? Well, she was wrong. Well done for not listening to her. You got into an amazing school. The one you dream about? Yeah, that one. And then you become a pretty successful actress. To the point a lovely charity wants you to be part of their campaign to inspire their young people.

You've got lucky. But it's only a little bit about luck. You worked really hard and believed in yourself harder.

Your determination gets you places; use it every day. Even in the small things. It's your superpower.

There are tricky times. There's bound to be, that's life! Mum tells you to drink water all the time and it's annoying but you don't listen and you end up in hospital a couple of times, which is more annoying. You get better at listening when it comes to things like that but you're still not the best at it. You're working on it!

Oh! And the world adapts to you loads. Ramps and lifts in most places now. Cool, right?! It's all good Amz. Trust yourself. You can do it. And you do. Enjoy your life, it's great!

Lot's of love from,
You

PS: Get over that boy quicker when you're 18. You never think of him in your 20s.

Amy Conachan, Actor



Your determination gets you places; use it every day. Even in the small things. It's your superpower.

Kareemah's Story

Kareemah was born with the genetic condition, Sickle Cell Anaemia, which affects haemoglobin and can lead to a pain crisis and sometimes other complications. Her Roald Dahl Transition Specialist Nurse, Giselle, has helped her move from child to adult health and care services.

Now a young woman in her 20s, Kareemah wanted to describe her own journey and the part Giselle has played in helping her.

My Sickle Cell affects me a lot. I get a lot of pain which I take medication for, but I try not to let it interfere with my life too much. Because of my Sickle Cell, I had a stroke when I was three and that affected my mobility on my left side, which means I walk with a limp.

Having Sickle Cell has had a big impact on my life. It has affected my schooling a lot and I missed around a year.

It affected my friendships and learning in general and then it has affected my everyday life.

I've had Sickle Cell crises before, and I had quite a bad one and ended up in hospital in June and didn't come out until August.

When I was in hospital, my Roald Dahl Specialist Nurse, Giselle helped me a lot. She turned into my hospital mother and I spoke to her every day!

Giselle did a lot for me. One day, when I felt I couldn't get out of my hospital bed, she got me up into the bathroom, showered me, sorted out my room and helped me get ready. Giselle would also come and have a little talk with me to make sure I was sleeping.

During my time in hospital Giselle would also take me for walks to the shops to get necessities.

If I didn't have Giselle's support, it would have taken a big toll on me. There are a lot of things that I would have kept in and that would have been stressful, and stress can trigger a Sickle Cell Crisis for me.

I can go to Giselle whenever I need to for advice and anything I need help with. When I don't understand something about my condition, I can ask her.

My experience of going from child to adult services was a lot less stressful because of Giselle. In adult services, you have to take on more responsibility, where in children's services, it was mostly my mum doing the speaking.

Giselle has helped ensure that I know how to speak to the doctors myself. She has taught me a lot and helps me get my point across to the doctors. She has introduced me to people who have helped me with my life more generally too.

She is someone who is always there, and I can call her whenever I need to.

I can go to her for everything. If I didn't have the support of my Roald Dahl Specialist Nurse, I would be struggling a lot. I think I would feel a bit lost in the system.

It's great that Roald Dahl's Marvellous Children's Charity is providing nurses who specialise in transition. I think it's a very important role.

I feel like children who have to manage a health condition can get lost and feel overwhelmed when they move to adult services.

Having the support of a Roald Dahl Specialist Nurse like Giselle makes you feel more at ease, less stressed and that you can handle things.

Victoria Ekanoye, Actor



**Protect your body like
the precious rare jewel that it is.**

Victoria is best known for playing Angie Appleton in ITV's *Coronation Street*, and Rachel, Liz Hurley's sidekick and PA, in *The Royals*. Victoria starred in CBBC's *Almost Never* opposite Kimberley Wyatt (Pussycat Dolls) and made her Netflix debut as Mistress Nightshade in the hugely successful reboot of *The Worst Witch*. She has guest starred in BBC's *Doctors* and in a Christmas Special of *Celebrity Mastermind*. Victoria wowed audiences, judges and artists alike on ITV's *Celebrity X Factor* and has since been busy in the studio writing her own material and recording guest vocals on a number of exciting new tracks. She is an active supporter and Patron of Sickle Cell Care Manchester.

Hey you,

Is today a good day or a bad day? I know it can be tough not knowing what you'll wake up to, but I'm so so proud of how well you're doing. It may not seem like it right now, but I promise there is so much joy and happiness coming your way. You're unique and brave and one day you will be an inspiration to others! Just remember, each time you have a crisis, the pain you're feeling is only temporary. Try your best to breath through it and focus on how much better you'll feel when it's over.

Think of your body like a plant – plants need food and water and light. Sometimes they even need medicine too, but most of all, they need love. To be taken care of. And you're the best person for the job! Eat your greens, plenty of fruit and vegetables, lots of water every day, and try to get some fresh air and

exercise so that your body can cope well with your condition. Everyone likes a treat, so there's no need to deprive yourself of that, just think of it as a reward for treating your mind and body so well!

When you feel tired, rest, there's no need to push yourself to exhaustion. Try to find some shade if it's too warm and wrap up as snug as possible when it's cold. Protect your body like the precious rare jewel that it is.

If you're struggling with your studies or concentrating in class - talk to your teacher and your parents; everyone is here to help and you don't have to suffer in silence.

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If you're feeling low or sad, talk to someone about it. It's so important that you share your feelings with someone you trust, you never know, they may be able to give you some advice that will make life feel a little better.

You could even join a support group! I know there are so many other amazing people with your condition, they may suffer differently to you and you can talk about ways you all get through. You'll also see that however hard things are, there's always someone having a tougher time and although it doesn't mean what you're dealing with isn't important, it will help put things into perspective and give you so many reasons to be thankful.

Now, I know it's not top of your 'favourite things to do' list, but it's so so important to attend all of your hospital appointments and take your medicine regularly. Remember your body is special and needs extra love and care and the doctors want to help you live the best life you possibly can.

Just between us, I still feel it's a little unfair sometimes that I have this constant hurdle to jump over, but we're athletes and our specialist sport is LIFE! Be kind to yourself and understand that you are loved and special and there is no one like you in the whole world.

This condition does not define you, nor will you allow it to get in your way! Your future is brighter than you could ever imagine and your dreams are waiting for you.

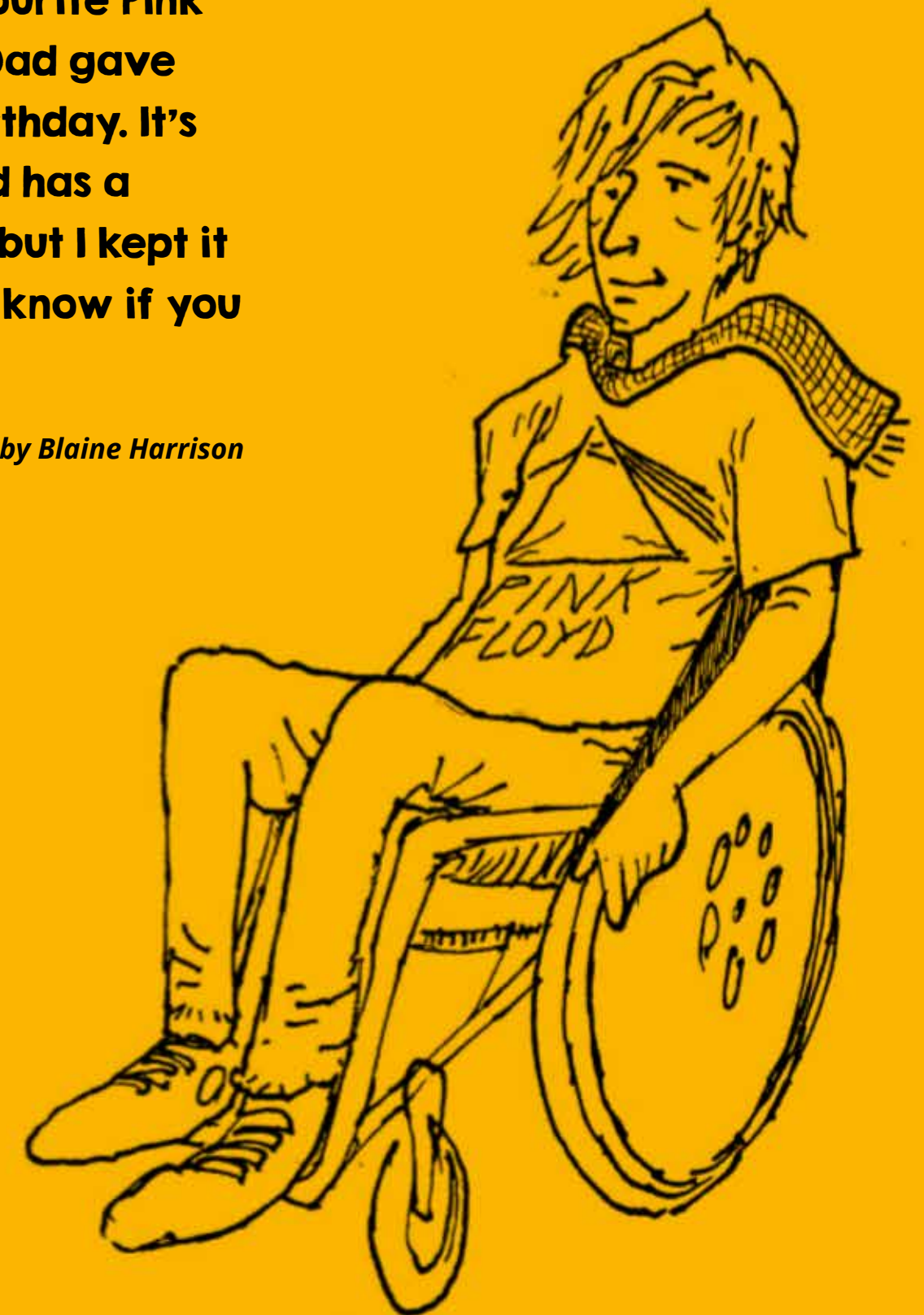
So stay positive, be the warrior that your are and above all else love yourself as much as you do everyone else. If you treat your mind and body like they belong to someone you really care for...nothing can stop you!

All my love,

Victoria xx

I still wear your favourite Pink Floyd T-shirt which Dad gave you for your 10th birthday. It's quite faded now and has a couple of holes in it but I kept it safe for you. Let me know if you need it back.

Self-portrait by Blaine Harrison



Blaine Harrison, Musician



Never stop fighting back. How I wish I could travel back in a time machine, so I could be in your corner when no one else would.

Blaine is the lead vocalist and co-founder of Mystery Jets. The British Indie rock band have released six UK top 40 albums, with their critically-acclaimed sixth record *A Billion Heartbeats* emerging in April 2020. Blaine was nominated for an Ivor Novello Songwriting Award in 2017 and has also forged his reputation as a producer and co-writer, collaborating with artists as diverse as The Waterboys, Beyond the Wizard's Sleeve, The Shoes and Rudimental. Blaine was born with the disability Spina Bifida and is passionate about campaigning for greater inclusivity in the music industry.

Dear Blaine,

I am writing to you from the year 2020; which will seem like a distant lifetime away to you and I suppose it is. I'm in my mid-thirties now and the world I live in is experiencing great unforeseen woes, but you have more than enough of your own, so don't waste time worrying about mine. Born British and uprooted to France, you've always felt unsure of where you belong. But you will come to look back on the feral freedom of your childhood years as some of your happiest.

You view your disability as a negligible hindrance; and refuse to let it stop you hurling yourself down hills in your wheelchair, or over dirt jumps on your BMX.

The trials of your early teens will be horrid. A time of tedious hostility. School meatheads will kick your chair and call you names which I will not remind you of. Not wanting to be labelled a 'snitch' you'll take your anguish out instead on people who love and accept you as you are (you'll be sorry for this).

Some mornings you will mangle by convincing poor Mum to call in sick for you, dreading what horrors await at the school gates. But other days you will fight back. Never stop fighting back. How I wish I could travel back in a time machine, so I could be in your corner when no one else would.

Solitude is your oldest friend, but it seldom finds you lonesome. Though you'll never be a pack animal, you'll soon meet fellow adventurers who also carry the fire. Stick with the warm people, you'll have plenty of

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time to be cool when you're dead. So young adventurer, go seek refuge in the school's art department, where you'll find a safe space amongst the canvasses and turpentine.

Music has also long been calling your name, you'll find a drum set in one of the practice rooms to help channel your angst.

Crotchets and quavers will forever give us both headaches so put your trust in your ears, they will be your greatest tool. Over the coming years, songs will fall from the sky and into your lap from time to time. Their arrival will bring you great comfort, as they will to many others. Your virtues, even if in a rage will keep you warm until the storms have passed.

Before long, a beautiful classmate with a blonde ponytail and a blue bowling bag will enter your world and turn it upside down. You will recognise something in her which mirrors something in you. When you decide to leave your wheelchair in the car boot one morning and take up crutches instead, it will be so that your eyes can meet hers on the same level. She's also the reason you'll take up smoking (yes it does look cool, well played). I'm sorry to tell you that in time she will slip through your fingers. But before she does, she will ask for your hand to the leavers' ball. And you'll never sit back down in your wheelchair again.

Society's view of the disabled will slowly change between your time and mine, and in due course, the wider public will begin to realise what we've known all along: It is the world surrounding us that is disabling, not the other way around.

You don't see people like 'us' on TV, on billboards, or headlining festivals so get out there and help create space for the kind of role models that people like us wish we'd had.

Although you stubbornly refuse to view your needs as different to anyone else's, you are not invincible. Listen to your doctors and ALWAYS put your health first (I'm still learning this now). Time has also taught me that disability doesn't just happen to an individual, it happens to a whole family.

Your appreciation of yours will grow endlessly with. each year that passes, and you'll even get to tour the stages of the world together.

And so, young scallywag, before I leave you be, let me say this: Everything you feel right now is

valid. The challenges facing you will thicken your skin, but never let the voice of other people's opinions drown out your inner voice. Somehow your heart already knows what you truly want to become. And always try to remember your mum's favourite words: "There is something in everything to be glad about, if you keep hunting long enough to find it."

Blaine xx

P.S I still wear your favourite Pink Floyd T-shirt which Dad gave you for your 10th birthday. It's quite faded now and has a couple of holes in it but I kept it safe for you. Let me know if you need it back.

Cerrie Burnell, Actor



The most radiant and rebellious thing you can do, is to fall in love with your body. And you will. But it will take work.

Cerrie is an actress and writer best known for her work on *CBeebies*, a role that has earned her critical recognition and a devoted fan base. Alongside this she works very closely with a number of charitable organisations linked to childhood and diversity. In 2011 Cerrie was named in *The Observer's* top ten children's presenters and in *The Guardian's* list of 100 most inspirational women. Cerrie is author in residence for Great Ormond Street hospital and a patron of Polka children's theatre. Cerrie's other credits prior to *CBeebies* include *Eastenders*, *The Bill*, *Holby City*, and *Comedy Lab* for Channel Four and various plays, including *Winged*, an original play she wrote and starred in at the Tristan Bates theatre.

Lovely Girl,

There is nothing I can tell you about how or who to be, because you never listen to anyone. Not really.

You are your own storm and with time, will be your own lighthouse.

This is not always an easy way to be, but you are not drawn to easy pleasures. And yet, you find joy in humble, bright things. Sunshine. The sound of the gulls. The moon at midnight. Don't lose these things, even if no one else appreciates them, keep saving them up in your heart because one day you will weave them into stories. The most radiant and rebellious thing you can do, is to fall in love with your body. And you will. You will appreciate all of your femininity, physical strength and unexpected grace. But it will take work.

Luckily you are not afraid of hard things. It's the simple things, like finding your keys that flaw you. That never changes, your keys will always remain a great mystery!

Things will be calmer though. But not yet. There are so many adventures you need to go on first. Your determination will be your greatest asset. It will get you in and out, of trouble. It will get you to exactly where you need to be. One day you will step through a door and discover you have been fighting the wrong fight. All of the years you spent refusing to be defined by your disability, were only because you'd been told that being disabled wasn't beautiful, or alluring, or desirable. You will learn this is a lie, and that being part of the disabled community is the most wonderful, glorious thing ever. Getting the world to understand this is the real fight. You have much work to do.

So, shine your light for the world to see, and never stop smiling.



www.roaddahlcharity.org/donate

Dame Evelyn, who began losing her hearing from the age of 8, is the world's premier solo percussionist, performing worldwide with the greatest orchestras, conductors and artists. Her solo recordings exceed 40 CDs and are as diverse as her career on-stage. A double GRAMMY award winner and BAFTA nominee, Evelyn is also a composer for film, theatre and television. Evelyn was awarded an OBE in 1993 and has over 100 international awards to date, including the Polar Music Prize and the Companion of Honour. Evelyn is currently forming The Evelyn Glennie Collection with a vision to open a centre that embodies her mission to Teach the World to Listen.

Dear Me,

I look around myself and I'm surrounded by cows, sheep, hens, cats, dogs, rabbits, tractors, combine harvesters, a sharp north-east wind, rain, sun and so much more!

What an amazing platform I have for exploration and adventure! How lucky I am to be a farmer's daughter and to have the space to run around and to connect with something different every single day. Isn't that an amazing lesson in itself?

How can I connect or engage with something different every day, even if things seem the same or familiar? As a young musician learning piano and percussion I get so much

fun when I let my curiosity be free. It allows me to find things which are not marked on a musical score, similar to when I run around the farm and observe how the wind and rain play with my body and how I play with the wind and rain! I love engaging, connecting and accepting and therefore embracing all the wonders of my day.

How amazing to wake up each day knowing I have a story to tell and that I can be the story teller, the actress, the director, the 'anything I want'! This is my story. What is allowing me to open my mind to a clean sheet of curiosity each day? Is this a form of listening? But I'm deaf.

How can I listen and be deaf? Why am I being told that I should not be able to play music because I'm deaf? Or to go to a school for the deaf instead of a mainstream school?

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Dame Evelyn Glennie, Percussionist



Photo: Jim Callaghan

How amazing to wake up each day knowing I have a story to tell and that I can be the story teller, the actress, the director, the 'anything I want'!

Who is listening to my story?

In order for other people to listen to my story, I have to listen intently and honestly to myself. Sitting looking out of the window on a rainy day or sitting on the garden lawn or anywhere I decide (the world is my platform) gives me the chance to be with me! What may appear to be an outwardly lazy activity to someone else can be the most productive time for myself!

These precious moments give me the realization that I am not a person with deafness but I am a unique person no matter what. My family and medical team so much want to 'heal' me which I'm hugely grateful for but healing and listening are the same art. When I listen to myself I can better listen to others and they in turn listen more profoundly to me – and so the drum roll begins!

My story, all of our stories, are a bridge to every part of the world we decide to engage with.

Your story is just as precious and wonderful as my story and I want to feel your story!

Evelyn, no level of deafness will ever stop you from being able to listen because listening is much more than sound. Therefore, keep being curious knowing that not every day will be magic. Disappointments will come in sack fulls.

How sad and tearful I have felt when a lamb has died in my arms at birth or my pet rabbit, Sooty, passed away or when I fell off my bike and broke my pinky or the sight of seeing mum badly injured following a major car accident or when the doctors told me to go to a school for the deaf.

When I listen to myself I can better listen to others and they in turn listen more profoundly to me - and so the drum roll begins!

I'm quite good in that I can allow my disappointments and sadness to be felt and listened to. I simply chat to myself going through what I'm feeling. If ever there's an important voice to take note of, it's that of your own. This isn't about ego or being self-centered but simply making sure we're connecting seamlessly with ourselves which will help everything and everyone around us

to resonate through our very being in the most harmonious way possible. Another drumroll for the celebration of our unique stories! Happy listening, Evelyn, and keep being you. Lots of love,

Evelyn

James Moore, Actor



Find people who help you to feel good about yourself, friends that support you, and see the best in you.

James gained household recognition when he joined the cast of *Emmerdale* playing fan favourite Ryan Stocks, the long-lost son of Charity Dingle. A year later he won Best Newcomer at the National Television Awards. Accepting the award, James spoke about the significance of his casting in a mainstream soap, let alone winning an award voted for by the public. James says: "Growing up with a disability, I wish I had the self-confidence that I do now to know that if you push yourself, it is possible to get where you want to be in life. Be strong, know your worth and don't settle or compromise. Sometimes it can seem like an uphill battle, but really that's just part of the journey - nobody's travel through life is a straight line."

Dear James,

I know you probably think you have better things to do than listen to me, but just give me five minutes. Five. That's all I ask, okay? Okay. I'm sure you'll be appalled to learn that the 29 year old you is a vegan that spends an hour a day in the gym, but here we are. You gotta learn to look after yourself better. It's a long journey, but it'll be worth it, and one day you're actually going to enjoy, and look forward to, exercise. Insane, I know. But that's only part of the reason I'm writing this. I know you have a lot of doubts in yourself. You wanna be an actor, and everyone is gonna tell you it's too ambitious, or unreasonable. And I get that - there's no disabled people on TV, really, and representation is pretty bad. But you should audition for drama school. Cause it's gonna get better.

Your confidence isn't great, but that'll improve too. Find people who help you to feel good about yourself, friends that support you,

and see the best in you. Surround yourself with people who encourage you and you can encourage too. Wear clothes you think you look good in. If someone sees you walking and laughs at you, don't let them get to you. Why are you so worried about the opinions of strangers you don't know and will probably never see again? It's okay. When you do get more confident you'll learn to shake it off, ignore them, even confront them. But don't let them get to you. In conclusion, one day you're gonna do pretty good. You'll have a good job and a good life, and I can't really tell you more than that - trust me, I've seen *Back to the Future*, this info can be dangerous stuff. But you should follow your dreams, and don't be held back by disability. You're more than your condition. Always.

Regards,
Future James



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Paige Murray, Para-athlete

Paige is a racing wheelchair athlete from Leicester. She had her first competitive track session in 2014. She made her debut for Great Britain in 2015 for the Sainsbury's Anniversary Games held at the Olympic Park Stadium. "It was an honour, privilege and a dream come true to perform on the iconic track that was home to the London 2012 Olympic and Paralympic Games. What an incredible experience. This opportunity provided me with greater focus, drive and ambition to succeed to the very best of my abilities."

Paige, you are amazing!

You are mid-way through your adolescent years, life is challenging, it is screaming at you from all directions. Breathe and mute the negativity the best you can.

Amongst all the screams (medical struggles, academic challenges, peer pressure and unnecessary scrutiny) caused by Cerebral Palsy, you are fortunate to be surrounded by your loved ones.

Attending the endless medical appointments pays off, so too do the many operations. And

guess what, physiotherapy is needed, you come to understand the importance of it eventually. Trust me!

News flash. You are an individual, everyone is an individual, no one person is the same. Stop exhausting yourself to fit in please. Be your unique self, it is a beautiful strength.

Push past your academic frustrations, work hard and be patient. You do achieve an English G.C.S.E in time. Congratulations! Your community and sports involvement, propels you to find purpose.



It will provide work ethic, spark aspirations and introduces closest friends. Your mental health takes a hit, severe anxiety takes over. It will restrict you. Be kind to yourself, get help. You will be okay.

You will be a Paralympic flame ambassador in 2012 - don't walk too fast!

A beautiful lady passes. Be strong. Studying continues for some time yet, college courses and apprenticeships. Be warned your brain hits a blank at the mention of maths!

Your Athletics Adventure begins! The Matt Hampson Foundation supports you, this is a life changer! You PASS your driving test and maths, FINALLY! You become an athlete.

Unemployment sees you start a business. You move out. You get that dream job. Tough circumstances arise, you become lost, not for long. You keep going. You find your greater self! Yoga takes you on quite an adventure. YES you learn yoga! You realise that Cerebral Palsy is no different to a brain injury. You find love with a true gentlemen. The best accomplishments are still to come.

Ruth Madeley, Actor



We make the world so much richer and more beautiful everyday that we show up as ourselves, exactly how we are.

Ruth Madeley is a BAFTA nominated actress, named as one of BAFTA's Breakthrough Brits in 2017. Ruth features in *The Watch* for BBC America, the adaptation of several Terry Pratchett novels, starring opposite Richard Dormer and Lara Rossi. Ruth has also starred in BBC One/HBO series *Years and Years* written by Russell T. Davies as 'Rosie' alongside a stellar cast including Emma Thompson, Jessica Hynes, Rory Kinnear, T'Nia Millef and Anne Reid. In 2016 Ruth was nominated for a Leading Actress BAFTA award for her role as 'Anne Watson' in the BAFTA award-winning BBC Three drama *Don't Take My Baby*.

Dear Little Ruth,

The world can seem a little bit overwhelming when you have a disability can't it? So much can seem unattainable; but, I want you to know that you have a so much strength inside of you and trust me when I say you can handle ANYTHING that comes your way.

First things first, people are going to stare at you sometimes because you look a bit different and there may be people who ask you daft questions about why you use a wheelchair. But that's ok, because your disability is ONE part of who you are and it's a beautiful part that the world needs to see.

It isn't ugly or something you need to 'overcome' or be embarrassed about. It's just another part of who you are, like the colour of your eyes or your taste in music (Kylie Minogue forever and always, kid).

Don't ever be afraid to talk about your disability!

Nobody knows your body or your needs better than you, right? Sure, you might need some extra help along the way with certain things, but that's when you need to speak up. Be clear in telling people what you need so that you can live the life you want - ACCESSIBILITY IS YOUR RIGHT, NOT YOUR REQUEST. Never forget that.

continued 

Your disability will mean that you'll need to spend more time in hospital and attend more doctor's appointments than you'd like. You won't want to do any of it, but trust me, it's necessary. Looking after your health is really important, because you've got a VERY full life to live with loads of incredible opportunities that you need to make sure you're well enough to enjoy! Nobody wants to take a load of meds or sit in hospital for hours on end, but if that's what it takes to stay well then we've got to do it, ok?

Rest is important. I know that you're always wanting to be out and about doing things, which is brilliant; but you need to give your body chance to recharge too. So make sure you rest, get enough sleep and eat healthily... treats are absolutely fine too every so often.

My last bit of advice is for when you're feeling a little bit low in confidence. Everyone feels that every now and then so try not

to stress about it too much. I promise you, your confidence will grow as you get older. We make the world so much richer and more beautiful everyday that we show up as ourselves, exactly how we are; and by doing that, you'll inspire confidence in others around you. You won't always feel like it, but you've got so much to give. So many people are going to want to meet you, and believe me, you have got so many epic things coming your way – just you wait and see.

So be strong, be proud, be kind to yourself and make sure you keep shining on. The world needs your light.

Love, always,

Big Ruth x

Florence's Story

A Roald Dahl Specialist Transition Nurse is not just there for the young person – they support the whole family. It can be as difficult for parents and carers to navigate the system between children's and adult services, as it is for the young person.

Whereas before, a parent or carer could be used to dealing with appointments, medication, consent forms, education and a whole range of other issues – it can be a different world.

For example, they will have been used to seeing familiar faces in children's services – that is different when their teenager moves to adult services where they do not know anyone and when they have to explain their child's condition over and over again to new professionals.

The family often rely on home visits and supportive texts and phone calls in children's services but these do not always feature in adult services. As teenagers get older, they have more rights and responsibilities which is a also difficult transition for parents and families who have looked after the child and taken decisions for them for many years.



Here, **Florence** shares her story about what it was like when her son and daughter – who both have Sickle Cell Anaemia – were supported through transition by Roald Dahl Transition Specialist Nurse, Giselle.

Oh my goodness, I feel like Giselle is family now!

My son has known Giselle from the age of 16 or 17 before he moved from children's to adult services. His transition to adult services was delayed as he had so many things going on due to his Sickle Cell.

He had a very difficult time with his condition throughout his childhood and had his first Sickle Cell crisis (episode of severe pain) at just 11 months old. Since then, he has been in and out of hospital up to four times a year with pneumonia, chest infections and pain.

He's grown up with it, but he has been very focussed and determined. He got A stars for his A Levels and got a 2:1 in BSc Psychology at university. I think he's been able to manage his condition so well because I've pushed him as a parent but also because of people like Giselle who have given us that additional support.

When you have a child with a medical condition there is so much to think about. When registering my son at university, we had to consider what systems were in place to support him if he became poorly.

We had to contact all the disability units within the university. Giselle was brilliant and provided letters of support and advice on what we should do.

Moving from children's to adult services is difficult as you're suddenly an adult and you have to push for things by yourself.

Having someone like Giselle that my son can relate to and feels able to ask questions of and is at the end of a phone or email, is incredibly useful and important. I think that without Giselle, he wouldn't have been able to navigate the system to get the reassurance and questions answered that he needed.

My son is confident about his health now and I don't worry about him. He is totally independent of me and I think that's because he has Giselle by his side.

My daughter had a relatively unscathed childhood with her Sickle Cell in comparison, but she has recently developed a number of related issues including problems with her bones, scoliosis and a problem with a valve in her

heart. She hasn't had infections or crises like her brother, and she grew up relatively pain free but around 14-15, that's when she realised what it means to live with the complications of Sickle Cell.

She recently had her gall bladder removed and has had a number of dizzy spells. A scan showed silent strokes, which can damage the brain.

My daughter has had a hard time mentally over the past three to four years as she isn't used to going in and out of hospital.

It's affected her schooling. She's missed a lot as she suffers badly from anxiety. She should have been receiving her A-Level results this year, but she couldn't attend to do them as she just had bad panic attacks.

My daughter trusts Giselle and knows she can go through her for her medical needs. She gets anxious in social settings with strangers and having Giselle there, someone she trusts and can talk to, is so important for her.

The first time we met her, she gave us a leaflet explaining what would happen moving to adult services. Giselle fixed an appointment where my daughter and I were introduced to all the relevant healthcare professionals she would be seeing in the adult department, which was a really good thing.

My daughter sees a cardiologist at one hospital, an osteo surgeon at another for her scoliosis and a Haematologist Consultant at a third for her Sickle Cell. That's a lot of different things and different people to manage. The system just expects that as you turn 18, you are able to have all those conversations to balance those things.

The period of moving to adult services is so important and having someone like Giselle who knows the young person's back story and has built a relationship with them and is able to advocate for that individual and tell a more holistic story, is priceless.

Dr. Sarah Gordy MBE is a professional actor, dancer and model. Her TV credits include *The A Word*, *Strike: The Silkworm*, *Upstairs Downstairs* and *CBeebies Bedtime Stories*. She played the lead role in *Jellyfish* at The National Theatre and danced in *The Rite*, re-envisioned at The Royal Opera House. In 2018 Sarah received her MBE for services to the arts and people with disabilities. She also received an honorary degree from the University of Nottingham in 2018. Sarah has been a celebrity ambassador for Mencap since 2013. In 2015 she became a patron of Circus Starr and in 2019 a patron of the Cutting Edge Theatre Company.

Dear Sarah,

Hi, it's Sarah Gordy writing from 2021. I'm writing to tell you about some of the things I love to do, because I'm sure you will too. Because I am you – all grown up. I love to exercise. I do it nearly every day, sometimes I do workout videos and other times I dance. It gives me so much energy and makes me feel strong. It may not seem like it now, but Mum is right. It's good to eat healthy. I love it. Healthy food gives me energy and strength too.

You are different from many other kids. But that difference also gives you strength. It will help you achieve great things when you grow up. Things that no one with Down's Syndrome has done before.

Some people may worry about you now, but you can tell them not to worry.

Use your imagination and dream big.

Because one day you'll act on TV, dance on stage and have fans around the world.

So remember I love you. Lots of people love you. And lots more people will get to know you and love you. Be yourself. Believe in yourself.

Love from

Dr Sarah Gordy MBE

Dr Sarah Gordy, Actor



Jellyfish at The Bush Theatre. Photo by Samuel Taylor

Be yourself. Believe in yourself.

Jessica Kellgren-Fozard YouTuber



When the world shows you darkness and difficulty, keep smiling back. Hold on to the truth of who you really are and you'll make it through intact.

Jessica is best known for her Youtube channel with over 870k subscribers on which she talks about her life with disabilities and chronic illness in a positive, uplifting way. Jessica has two rare genetic conditions, called HNPP and EDS, (because life blessed her that way) which affect her nerves and connective tissues. Her condition can vary in severity from day to day, with at its worst her waking to find she cannot move her arms or legs. For this reason Jessica occasionally needs mobility aids. She is also deaf and partially visually impaired. She lives with her wife Claudia, their new baby and two adorable fluffy dogs in Brighton and is a notable figure in the LGBTQ+ community having been highly commended as one of the rising stars of the year by DIVA magazine and ranked highly on the 2020 Pride Power List. Jessica was rewarded for her services to the disabled community with an honorary doctorate from the University of Worcester.

Dear Jessie,

Yes, just as you've been hoping, this is 'future you; coming to tell you you're going to be okay and that you finally found a girl to date! <3 But you aren't going to 'get better' and I know that's difficult to hear... much like everything else is 'difficult to hear' at the moment and you should REALLY go and get that checked! (Hearing aids are a great idea).

You're very scared right now because you don't know how someone can function as an adult when their body is broken like ours.

That's just because you've never seen it before and the adults around you say it can't be done. Well I promise that it's possible.

You'll have the lovely home you dream of, you'll have the wonderful wife, you'll have close friends and a job you love... and you won't feel so terribly, achingly alone. And all of it will come because you refuse to give up on who you are, because you never loose yourself in the swell of pain and illness.

You're still that happy, optimistic, loving little girl you started out as.

When the world shows you darkness and difficulty, keep smiling back. Hold on to the truth of who you really are and you'll make it through intact.

With love,

Jessica xxx

Hi, I'm Ellie Wallwork and I'm a 21-year-old actor (*Dr Who*; *Call The Midwife*), songwriter and University student. I've been blind since birth with a condition called Retinopathy of Prematurity; I can only see light and some contrasts. I started acting when I was 11 and haven't looked back since! In my spare time, I love to read, write and campaign about all sorts of things, from social justice to LGBTQ+ and disability rights activism. I also study English Literature at the University of Leeds and I get involved with societies at uni as much as I can, to try and get mine and other disabled students' voices heard. Learning new things and meeting new people is something I've enjoyed from childhood to now, and hopefully always will.

Dear Ellie,

Spoiler alert: no, you haven't been transported through time. It's only me, your personal nightmare of an older self.

Time travel hasn't been invented yet and I know you're probably thinking this is some conspiracy plot like in the Young Adult books you read but listen up, just for a second. (I still read Young Adult books, by the way; that hasn't changed). You're going through a tough time and I want to tell you straight up, it's okay to ask for help. You don't need to be strong 24/7. I know the fact that you can't see is really starting to hit you – you may have been like this all your life but it doesn't make it any easier. Besides the fact that you're a teenager with normal teenagery hormones, your mental health needs to come first. There isn't any shame in talking to your friends or your family about it; they're here to help you.

Keep writing and being creative – it's something you genuinely enjoy and take pride in. You don't need to build worlds around yourself to protect how you're feeling – instead, embrace those outlets. Not being able to see doesn't make you a failure; it makes you strong and resilient.

You can be bisexual and blind without having to have an identity crisis every day - you're valid and don't let your brain tell you otherwise.

Also, you're good at acting. You can write songs and tell stories. Don't let that self-doubt eat you alive – life's way too short to be caught up in the traps of Impostor Syndrome. It's going to be okay, I promise. You're going to grow up to become someone you'd be proud of now.

Lots of love, **From Ellie xx**

Ellie Wallwork, Actor



Not being able to see doesn't make you a failure; it makes you strong and resilient.

Dr Frances Ryan, Journalist



Health is not linear, it ebbs and wanes and you will ride every wave.

Frances is a *Guardian* columnist and author. Named one of the UK's most influential disabled people by the Shaw Trust in 2019, her work has appeared in the House of Commons, National Trust, BBC Radio 4's *Woman's Hour*, BBC Radio 2's *Jeremy Vine Show*, BBC *Sunday Politics*, *Channel 4 News* and more. Her debut book *Crippled* was shortlisted for the Bread and Roses award 2020. She has a doctorate in politics from The University of Nottingham. Ryan was highly commended Specialist Journalist of the Year at the 2019 and 2020 National Press Awards, as well as shortlisted for the Orwell Prize in 2019 and the 2020 Paul Foot Award for Investigative Journalism.

Hello darling, I'm proud of you.

I should say that from the off. I'm proud of all the things that you will go onto achieve: a PhD; your first book; a column in a national newspaper; the perfect blow dry. I'm proud of the fact you did it all with low grade muscles, fatigue, pain, steps, and more chest infections than you can count.

You will be fearless with your health and it will only occasionally get you in trouble. Hold onto that; it is your greatest strength.

Don't let anyone restrict you, doubt or patronise you. Low expectations are not a natural side effect of disability. You have more potential than even you can dream of.

There will be bumps along the way, at least one particularly big one. But don't worry. Health is not linear, it ebbs and wanes and you will ride every wave. It is okay to cry. You will laugh too. Lots. You will drink wine in gardens with friends you love. You will speak in front of vast crowds and beam over the radio. You will tour cities with bright lights and see art, plays, and music.

Savour every moment and store them like light for the darker days.

Do not get the pink wheelchair. You won't be able to afford a new one until you're seventeen and no one wants to go to sixth form looking like Barbie on acid.

continued 

You will want independence – your own accessible home, dating, a support team – and feel frustrated at the wait.

You are not in competition with your non-disabled peers, nor a hypothetical healthy version of yourself.

There is no timeline. It is not a race. The destination changes, and is none the worse for it.

Stretch. Move, even when it doesn't feel necessary. There will come a day when your body needs more help and you will be grateful you gave it a head start.

You will thrive at university. It will be a little scary to be the first generation in your family to study a degree, and you will often be the only disabled person in the room. But that's okay.

You will learn and grow and be inspired. One day you'll even teach.

Try salad before your twenty-fifth birthday – vitamins and minerals are your friend – but don't neglect pizza and crisps either. Too many carbs did not wreck your genetics – despite what Instagram wellness ads tell you – but they do taste really good.

Talking of which – don't stop going to the dentist. Yes, clinics aren't made for wheelchairs but you deserve access to all healthcare like anyone else. That goes for cervical smears too.

Never be self conscious of being different. Your disability is not your defining characteristic, nor an inconvenience to hide.

It is a part of you and one that will make you kinder and wiser than many born in fully working order.

There are no limits to what you can do. Sure, you can't be an elite marathon runner...or even an average one. But there is a big world

out there and it is yours to explore. You will get a career you love, and spend each day with passion and purpose. Just because you don't see anyone in the media that looks like you growing up doesn't mean you don't belong there.

You don't need to avoid a doctor's office for a decade but you don't have to be tethered to one either. Enjoy the freedom of good periods of health and use the NHS as your helper when the bad ones come. The bad ones inevitably come, and when they do you will find yourself

lifted by the type of strength that cannot be reduced by a muscle weakness. Don't be afraid to question medical professionals, or challenge them for more. You are your greatest advocate, best cheerleader, and the most qualified expert on your body.

And before I go, there's just two last things to always remember: how special you are to be unique, and how lucky the world is to have you.

Love Frances x

You will get a career you love, and spend each day with passion and purpose. Just because you don't see anyone in the media that looks like you growing up doesn't mean you don't belong there.

Aaron Morgan, Racing Driver



Photo: Darren Cook

You may not believe it now, but one day you're going to be the one inspiring others.

Aaron is a GT4 driver for all-disabled racing team, Team BRIT. Aaron was a keen motocross racer from the age of 7, and in April 2006 he had an accident whilst riding a jump on his favourite track, causing him to break his spine. He was in a coma for almost four weeks, followed by a lengthy period of recovery at the Duke of Cornwall Spinal injuries Unit in Salisbury, Aaron returned to study, eventually achieving a 2:1 in Sports Science at Brunel University. He then returned to his passion for motorsport, becoming the youngest disabled person to achieve a National B Race Licence. Since 2014, Aaron has raced as the only disabled driver in the BMW Compact Cup Championship.

Dear Aaron

You're in a situation which may seem bad right now, but it will get so much better if you want it to.

I need you to do everything you can to believe that there is a positive way forward and you will be happy and confident again.

Set yourself little goals to get you to your dreams.

Look for role models along the way and use them to inspire you towards your goal. You may not believe it now, but one day – you're going to be the one inspiring others.

Speak openly about your problems and people will help you along your journey. Stay true to yourself and rely on your friends and family for support.

With a positive attitude only positive things can happen to you. This is not the end of the racing that you love - a whole new racing journey is just around the corner.

Get busy living.

Aaron Morgan

My name is Joanne, I'm in my early 30s and I'm *Hollyoaks* actress, Amy Conachan's twin sister. I studied Fine Art in West College. I now work as a sales advisor for Three mobile and live just outside Glasgow where I live with my partner Geo.

Hi Joanne,

It's you. But old... Well older. I just wanted to write to tell you to take a deep breath and let you know that everything's going to be ok. I mean your life does turn out different. A LOT different to what you expect it to. No spoilers or anything. But trust me it's going to be good. I (we're) only 31 right now but we are HAPPY!! For starters you don't get married when you are 23 and have a baby when you're 26, or become a famous fashion designer like you thought you would. But when you get to those ages you don't want those things at that time! You're too young!! And of course there has been bumps in the roads.

Being diagnosed with epilepsy at 14 was no walk in the park but we get on with it. It does not bring you down. Life is for living!

And now. NOW. You are madly in love and you live with your partner in such a lovely little house with your whole future ahead of you. Amy is doing amazing in her life and so is Mum & Dad. They're all happy and so successful in their jobs. Happiness is the most important thing, Jo. Keep that in your mind all the time. Not money, fame or power. All I have to say in terms of advice is try each day at everything you do and be proud of yourself.

Listen in school, do your homework and study hard.

There is a reason why all the adults are saying it now. But seriously everything is going to be fine.

Love and happiness is what get you through each day. Just you wait, well done so far!

You at 30.X

Joanne Conachan, Sales Advisor



Happiness is the most important thing. Keep that in your mind all the time. Not money, fame or power.

Luke Pound, Racing Driver



Photo: Darren Cook

Even when you become disabled, it's this calm, collected, sensible mindset which will mean you'll be just fine.

Luke is a driver for all-disabled racing team, Team BRIT. Luke had an accident on his motorbike in 2011 resulting in brachial plexus injury – the breaking of all five nerves into his left arm. This has left him with no movement in his left hand and very little movement in his left arm. A planner for DHL's Tradeteam, Luke came across Team BRIT online and got in touch to find out more about its Racing Academy opportunities, being a lifetime fan of racing. He joined the team for two track days in April 2020 and was invited to join the team as a rookie. Luke now races in one of the team's BMW 116s in the Trophy Category of the Britcar Championship.

Dear Luke,

It's fair to say you're a pretty chilled out guy. Not a lot phases you, you take life as it comes, and despite your young years, you have a pretty sensible head on your shoulders.

For that reason, I'm not writing to give you advice on how to deal with the challenges of life ahead. Instead, I want to tell you how well you're doing, and to stick to who you are.

You're a problem solver. You're creative, and great at finding ways to achieve what you need or to get to where you want to be.

You're relaxed and take life as it comes, you find a way to laugh and joke in almost any situation.

These qualities are going to get you through difficult times with a positive attitude, and even when you have to make some changes to your life when you become disabled, it's this calm, collected, sensible mindset which will mean you'll be just fine.

Your determination will see you join an all-disabled racing team, competing against able bodied drivers, and you'll become an inspiration for others.

Keep being you, Luke – don't take life too seriously – it's just one big adventure.

Luke Pound

Vanessa Wills,
Pharmaceutical Sciences



**Trust your instincts and be kind to your body.
Listen to when it is telling you to
slow down or rest up.**

I'm Vanessa, I am 39 years old and I have Sickle Cell Disease. In spite of my illness, I have been a guardian and carer for my two younger siblings, one of whom also has Sickle Cell, after my mother passed away. I obtained a first-class degree BSc in Pharmaceutical Sciences and spent 10 years working in the pharmaceutical industry in Quality Assurance roles. I am part of the West Midlands Quality Review Service Peer Reviewing team, which audit hospitals with Haemoglobinopathy departments to ensure that they are providing good standards of care. I also work with Roald Dahl Transition Specialist Nurse, Giselle at King's College Hospital, to do talks, mentoring and educating patients on transitioning into adult care, maintaining self care and sharing life experiences.

Dear Vee,

It's me, your future self here...Heey!

I am not writing to you with any wowtastic miracles from the future like winning it large on the Lotto lol, however I can enlighten and encourage you with the wisdom I have attained. As we know, you have Sickle Cell Disease (SCD) although you'll prefer to say 'Sickle Cell Anaemia' because of the negative perceptions/connotations associated with the word 'disease'.

I won't lie to you, the next 20 years plus will be hard and have its challenges.

The first good news that I can provide is that (contrary to medical advice given out in the '80's) it is possible to live past your late teens

to early twenties, well into your fifties and sixties at least. Your desire to learn everything you can about SCD is a good one so keep it up.

The better you can understand your body & illness/disability the better you can protect yourself.

Trust your instincts and be kind to your body. Listen to when it is telling you to slow down or rest up.

Layer up to keep warm. Keep well hydrated and eat a balanced diet wherever possible. Yes sweets will help give you a nice energy boost but so can B vitamins, along with other vitamins and supplements to help support your body's needs. Hospitals will become your second home but that's ok because it's all part

continued →

of what will help to keep you as healthy and well as possible. Both studying and working will have their difficulties.

There will be limitations that are specific to you. It's sad to say but, you will face prejudice, judgements, ignorance and lack of understanding at times. However with patience and education there will come an opportunity to knock down some of those barriers. Finally I know that there will be times when you will feel frustrated by the seemingly endless restrictions and things might start to feel overwhelming but it's not the end of the world.

There will be ways to be sensible and still actively live your life and do exciting things like travel: Barbados to Kosovo and everywhere in between.

Have a cocktail or three with the girls. Swim with dolphins even though you can't actually swim. Ride a horse despite being terrified of such a powerful, beautiful beast. Then spending the next three days after trying to remember how to walk. Yes we will accomplish these and so much more.

Finding a good work/life/sensibility balance is key to your success. You have way more love, strength, determination and motivation than you give yourself credit for.

Through your passion, knowledge and education you will go on to inspire others, saving lives including your own and contribute towards enlightening and supporting a network of warriors.

You are INCREDIBLE and you need to learn to have more confidence and love for yourself, same way you have for others. Stay blessed.

Love Always,
Vanessa

PS. Caffeine is not our friend.



" I love being a Roald Dahl Transition Specialist Nurse. It's a privilege to improve the pathway for young people with chronic conditions as they move to adult services. "

Bethan, Roald Dahl Transition Specialist Nurse

*Help us to establish more **Roald Dahl Transition Specialist Nurses** like Bethan.*

*Please contact:
fundraising@roalddahlcharity.org for more information on how to get involved.*

www.roalddahlcharity.org/donate

Max is manager of eTeam BRIT, the sim racing arm of all-disabled, Team BRIT. Max, who was diagnosed with asperger's syndrome at the age of 10, started working with the team in the summer of 2019 as a driver before taking on the role of Team Manager in April 2020. Max has been sim racing for 12 years using platforms including rFactor, iRacing and Assetto Corsa. A huge F1 and BTCC fan, Max has also raced in the real world, competing in the 750 Motor Club Locost Championship. As well as racing alongside the team's disabled drivers, Max's role includes the day to day running of the team and coaching in the sim racing academy.

Dear Max

Now that you've started secondary school,

I know your feelings of being 'different' are stronger than ever.

You think you're 'the weird one' and are starting to feel a sense of acceptance that this is just the way things are.

Ever since you received your diagnosis of Asperger's Syndrome, you've almost used it as a 'safety blanket', blaming everything on the Asperger's rather than looking deeper at anything else. I can't blame you to be honest. Kids are mean!

You are different to some of the others in your classes and sometimes they really let you know it, but that will get better. They'll grow up and grow out of it. Soon, you'll hit your turning point. In a few years, you'll watch London host the Olympic and Paralympic Games and you'll see that having a disability can actually

be something that you drives you to focus on what you can do, not what you can't. You'll see stadiums full of people being inspired by the most incredible athletes who certainly haven't used their disability as an excuse, and you'll realise, that's exactly what you want to become.

Autism and Asperger's aren't very well understood in the world you're living in but people are becoming more educated in these conditions, so the world will become more accepting and you'll work out who you are.

You're a Spooner, and what's our family catchphrase? "You'll never forget a Spooner!" You're being brought up to be proud to leave a lasting impression on the people you meet - now just make sure you focus on making that impression positive.

Max Spooner, Online Racer



Stop using your Asperger's as an excuse - treat it as what it is - part of what makes you, 'you'.

Matty Street, Racing Driver

Matty is a BMW driver for all disabled racing team, Team BRIT. Matty was diagnosed with dyslexia, dyspraxia and Asperger's (a form of autism) when he was at school. At 12 he discovered karting, which had a huge effect on him and helped him manage the challenges that Asperger's can cause. He won a £30k scholarship to go racing at the age of 14 which opened doors to the expensive world of motorsport. He studied motorsport engineering then went on to secure a degree. He now runs Rochdale's TeamKarting, the UK's highest rated karting track and has won an award for being autism friendly. Matty has helped introduce numerous Autistic children to karting, some of which are now racing outdoors. Matty began racing with the team in 2019.

Dear Matty,

I bet you're worrying about what this letter will say. Why has someone written to you? What do they want? What have you done? Worrying and overthinking is what you do, right? I want to tell you that it doesn't have to be like that.

You worry and you over analyse because of your autism. It's not your fault, but there are things you can do to calm you brain, stop your worrying, and make life happier.

To you right now, everything seems huge and the smallest changes to your routine can you send you into a spin of aggression or stress. Remember how you felt when you had a new supply teacher and no one warned you? Or when you had to wear some new school shoes that didn't feel right?

I want to help you realise that you don't need to worry about these little things, which in the big scheme of things are so insignificant. You'll look back in a couple of weeks or a month and you'll realise it didn't matter. I also want you to stop feeling like you need to do what

Photo: Darren Cook



everyone else is doing and be like everyone else. You're unique, you're a good person, and you have to remember that. I know that right now, you're getting a hard time from people at school who don't like the way you are but I want you to know what's ahead of you. You might feel like you're the one that is never listened to, the one that no one wants to be around, but believe me when I tell you that the future is bright. Very soon, you'll find a passion for motorsport you

never knew was there. You're going to excel at school with the help of some amazing teachers that will finally understand what you need. You'll become a leading expert in your industry, a CEO and business owner, a racing driver for the most incredible team, and someone who others look to for advice.

Believe in yourself Matty - the future is what you make it.

Becoming a wheelchair-user at 17 changed the course of Ruth Fairclough's life, but not her desired destination; a career in maths. With pragmatism and a passion for her subject, Ruth has worked in the corporate sector and higher education, becoming Head of Mathematics at the University of Wolverhampton in 2013. 'My spinal injury drove some of my decisions. It didn't stop me going into STEM or being the best I could be, but it drove the way I got there.'

Dear Ruth,

First of all, you can forget about all those ambitions you have of being a pilot, or joining the army... It isn't going to happen as you're going to have a spinal injury soon that will make you paraplegic. Don't be too horrified, it isn't the end of the world and you will survive and thrive. The first few weeks on bedrest is horrible but after that, it will get better as you get your independence back.

You will fight fiercely to keep your independence, but perhaps you can ask for help occasionally, it isn't a sign of weakness.

You know what, some people actually like helping you and they get a sense of fulfilment from it, especially your family; be kind to them, as they only want to support you.

After your accident you will live life a little by a list of what makes a successful life (go to University, get a career, financial independence, get married, have kids etc) but there is no need to rush it. Your older self has run out of things to do on your list! Kick back and have fun a bit; do more sport while you are young as it isn't going to happen now as I am too old for competitive sport.

The spinal unit will emphasise how important it is to look after your skin – listen to them and follow their advice, don't do too much at the expense of your health. You still hate bedrest even for a few days so its best avoided.

There is more to life than a successful career. Nobody lies on their deathbed wishing they had done more work: remember that.

Ruth Fairclough, Mathematician



Your older self has run out of things to do on your list! Kick back and have fun a bit.

Bobby Trundley, Racing Driver



Photo: Dave Archer

Your autism is your superpower, and it will unlock the most incredible doors - find that power, no matter how small you think it is.

Bobby is a GT4 driver for all-disabled, Team BRIT. He was diagnosed with autism at four and from an early age, has found motorsport to have a profound impact on the way he copes with the condition. He is now the reigning Dmax champion, holding five titles, three time Endurance and two times Heats Champion 2017 and 2018. Bobby has been awarded the Anna Kennedy OBE, Autism Hero Award for outstanding achievement in sport and was awarded the ANCA World Autism Festival Excellence in Sport Award 2017.

Dear Bobby,

Life feels a bit difficult right now, doesn't it? You're probably wondering why you feel the way you do, and why you feel different to a lot of people around you. What I'm about to tell you will sound ridiculous, you won't believe it, but I'm asking you to try. First of all, your autism does not define you, your attitude does. The way you cope and live with what makes you unique will make all the difference. Here are a few lessons I've learned that I hope will help.

Trust those who love you when you are afraid or anxious, try to remain calm and accept their help when you feel overwhelmed.

When you are overwhelmed, listen to your inner voice and quietly remove yourself to avoid a full meltdown.

Find coping strategies that work for you. Never think it's weak to accept you need space. Have the confidence to try new things and push your limits. As time goes by, I promise you will become more resilient if you test your comfort zone just a little more with each challenge.

Your autism is your superpower, and it will unlock the most incredible doors - find that power, no matter how small you think it is.

continued 

Once you find what you love to do, use your incredible focus to be the best you can be. Find the exceptional you.

Never listen to doubters.

If you believe you can do something, find people who encourage your skills, not people who put barriers in your head and undermine you because you have a disability. Find the positive aspects of your disability, focus on what you can do, not on what you can't.

Disability will bring out the worst in some people's attitude toward you, don't let this discourage or bring you down. Always remember there are far more good people out there than bad. You will receive far more warmth, understanding and acceptance than you will the odd hurtful negative reaction from ignorant or uncaring people. Learn to move on and if necessary have no further contact with them.

Always remember, this is your life and you do not have to accept limitations others may put in your head or in your way. If you believe you can do something, surround yourself with those who believe in you, they will share your enthusiasm and together nothing will be unsurmountable.

You will live a fulfilling happy life if you believe in yourself, and by doing so you will help pave a way for those who follow. You're going to be racing GT4 cars as part of the most amazing racing team.

Bobby, you will be part of the revolution toward disability acceptance, equality and inclusion.

All the best

Bobby



*Help us to establish more **Roald Dahl Transition Specialist Nurses** like Giselle.*

Please contact: fundraising@roalddahlcharity.org for more information on how to get involved.

www.roalddahlcharity.org/donate

" I love being a Roald Dahl Nurse because of the opportunities that I have to share and give patients the best care possible. Part of my role as a transition specialist nurse includes helping the young person to navigate a complex NHS system, getting them ready for when they transfer from children's to the adult services, getting them used to having to speak up for themselves, helping to support them, mentoring them and giving them the tools that they need to progress in life. "

Giselle, Roald Dahl Transition Specialist Nurse

Mark graduated from De Montfort University in 1994 after obtaining an MBA in Business Administration. Though a Masters degree is a notable achievement for most people, for Mark this marked the culmination of years of hard work battling many obstacles. When Mark was five years old, he went from a happy, carefree child to becoming paralysed overnight. He had contracted the poliovirus, which by that point should have been eradicated from the UK. He was initially given a 10% chance of survival but not only did he survive – he thrived. His positive, can-do mindset has meant that he went on to become the Founder of several successful businesses. In 2018 Mark's autobiography, *I Can. I Will.* became a number one bestseller on Amazon. He was highly commended in the IoD Director of the Year (SME) 2016, in 2019 winner of the IoD Director of the Year (East Midlands) and East Midlands Leadership Awards Winner.

Dear Younger-Self,

Learn to love yourself because you can't expect other people to love you if you don't love yourself.

People have different starting points in life. Some will start in front while some people like you, will start at the back burdened with challenges.

The people at the front are no better than you. It is just that you've been given better opportunities and as a result have had a head start. They are not burdened by your disadvantages and as a result, can achieve success much quicker.

Run the Race of Life at your own pace, be consistent and be positive because you have what it takes to negate any disadvantages life has thrown at you.

Imagine yourself years later winning multiple business awards being chosen ahead of all those people who had a better start in life.

Work hard, stay focused and keep on trying. Never, ever give up.

Much love from your Older-Self.

Mark Esho, Entrepreneur



**Run the Race of Life at your own pace,
be consistent and be positive.**

Dave Player, Team Brit Founder



Photo: Darren Cook

**You can drive your car wherever you want
or you can be a passenger in that car.
This is the same with your life.**

Dave served as a Royal Engineer in the Army from 1983 –1988 and then suffered a spinal injury in 1991. After rehabilitation he set up his own businesses including managing international sporting events at European & Paralympic levels. He returned to the UK and wanted to work with injured troops, so set up the charity, KartForce in 2010. Dave designed a set of hand controls that could fit any kart, allowing drivers with a wide variety of disabilities to compete on a level playing field with able-bodied drivers. In 2015, Team BRIT was formed as an offshoot of KartForce, to give drivers the opportunity to compete in competitive car racing.

Hi Young Dave

You don't know this yet, but you are going to have some amazing adventures – beyond your wildest dreams. OK – you have a disability that makes life more challenging, but this is no excuse for not pushing yourself to achieve great things. Don't be lazy or use your disability to get out of doing things.

Doing new things and taking on new challenges can sometimes be scary, but you will feel amazing after you have completed them.

If you decide not to face these challenges, you will regret it. Look after your health, avoid eating food you know is not good for you and exercise.

Focus on all the things you can do and forget the things you can't do. Put all your effort into everything you do, be proud of yourself for doing the best you could possibly do and keep pushing yourself to improve. Imagine you

are the driver of a car. You can drive your car wherever you want or you can be a passenger in that car. This is the same with your life – you can take your life where you want to go. You are in the driving seat of your life. Being adventurous and brave, means you are going to travel to some amazing places around the world, meet some fantastic people and make great friends.

You're not going to believe this but you are going to be the boss of a motorsport racing team made up of drivers with all sorts of disabilities and you are going to help change others people's lives. The journey ahead is not going to be easy and you will come up against some huge obstacles. It is up to you how you face these challenges but every time you overcome one, you will feel on top of the world. You are going to have a mad crazy life!

Dave



Lily's Story

Seventeen-year-old **Lily** is a keen aerial artist, a creative spirit with a phenomenal memory. She was diagnosed with epilepsy when she was 14 and also has autism. Despite having eight or nine seizures a day and sometimes needing to go for stay in hospital, she performs on aerial silks, hoop and trapeze – “I love being upside down”, she says.

Lily practises thirteen hours a week in a professional studio which focusses on ability rather than disability, and helps manage Lily's seizures if one happens, even if she is in the air! **Her mum Mary** describes how Lily's Roald Dahl Specialist Nurse **Becs** is helping her move from children's to adult services, and to alleviate the concerns they all have.



Our Roald Dahl Nurse, Becs, has been amazing. She is full of practical advice.

She is a walking medical guru and really supports the whole family. Becs has built up a strong relationship with Lily and Lily trusts Becs implicitly. If Lily has any questions, she will talk to Becs rather than the doctors.

She helps us with managing Lily being under different departments at two different hospitals as that can be challenging and she sorts out prescriptions with the GP. She will also just phone and send an email asking how everything is and I've got to say means a lot. Sometimes,

when you are dealing with the medical profession, you don't feel on the same level, whereas with Becs I feel I can say anything and she 'gets it'.

Lily isn't at school any more. I have a budget to manage her education – like running a business, all logged and accounted for – and that will run until she is 25. I control Lily's medicine and I watch her take her medicine, that's not going to change any time soon.

The needs don't go away, the person just gets older and that gets lost.

The biggest fear for us in all areas of Lily's situation is the transition to adult services. When you get paediatric support, you get full support, it is very child and family orientated. Having had a little taste of adult services with her in hospital, I feel that changes.

The family isn't as involved and the hospital expects the little adult to be independent in their views. I don't feel that you can say at 18, “off you go”.

Every person at 18 is so different in terms of their experience and ability to be independent and for us as a family it really scares us. When she came out of intensive care a following a seizure last time – she was put into an adult neuro intensive care unit – the experience was traumatic for us. They said you can't stay – every time they wanted to try to do something for her, like turn her over, they asked us to leave the room. They moved her then to adult neuro ward because she was 16; we were in a room with ladies who had strokes, severe neurological problems – it was the most frightening experience for Lily.

Becs has been helping prepare for transition, including ensuring Lily has her voice heard within drug consents and accompanying her to adult services appointments.

She has stopped seeing the paediatric neurologist and is transitioning to transition consultant – that's where we are at the moment. When we do see Becs it's with him. They both came for a home visit, and he'd never done that before. That meeting was only successful because Becs was here.

Dr Alan Baum, Retired Lecturer

Alan was born in August 1942. He has had a scar on the retina of his right eye from birth which prevents vision except for the right-hand side of the eye. With the good left eye this gives him some sense of visual width. The condition was identified as the result of toxoplasmosis by a Harley Street specialist, Mr Williamson-Noble who he was taken to at the age of five, on the advice of his family doctor. Alan has since gone on to build a successful career as a lecturer and achieved a PhD. He is now retired.

Dear younger Alan,

I am writing to you at a ripe age and what a life you've had so far! You might have a sight impairment but because you were born with it, you have never known what you are missing and you will ultimately believe you have been able to experience the world largely as others do.

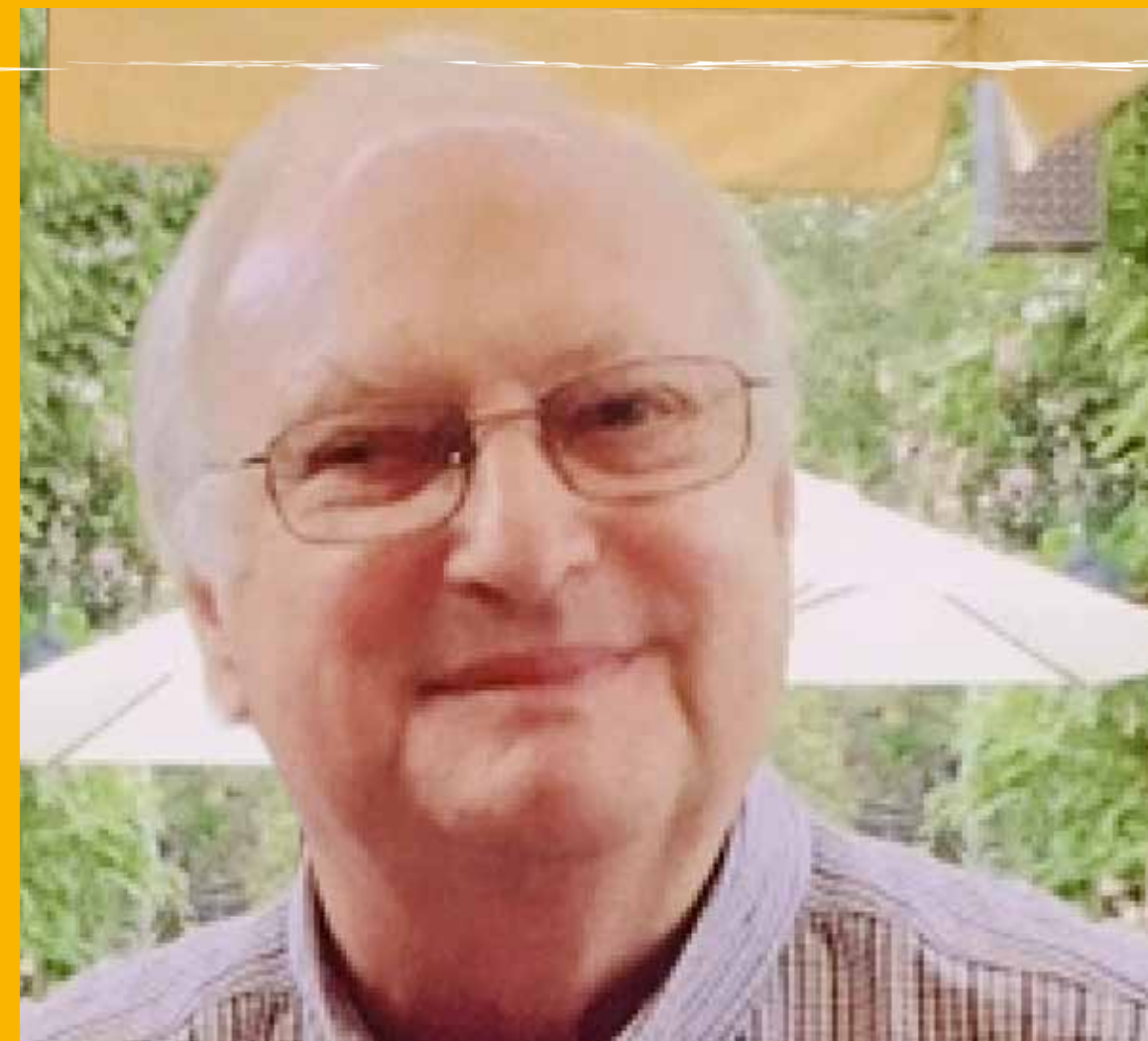
You will have to deal with some setbacks though and will discover that your dream of being a fighter pilot in the RAF is not an option thanks to your visual defect.

You will have a testing time when you get into grammar school.

You'll cope with the academic work well enough but there is a big emphasis on sport

and cricket especially will be a real challenge because of your sight. You'll feel inadequate as a result and you'll find it harder to make friends in this competitive environment. You'll be scared of the visual demands of some subjects especially the laboratory work in A-level sciences, so you'll opt for Arts subjects instead. You will have some regrets about this decision in future as you will think that you could have made a good career as a scientist and got more job satisfaction.

However, listen to your teachers – some of them will understand your situation and make life easier for you. You'll even be awarded school prizes in Chemistry and French! You will get a confidence boost when you go to



LSE university in London. You will find you're really quite good at table tennis and you'll even get into the college table tennis team! You will go on to be a Polytechnic and University lecturer. You will get married twice, have two children and four grandchildren. You will eventually gain a Ph.D. You will realise that you have had to make compromises in your life, especially when it comes to your occupation and your life chances have perhaps been narrower than you might ideally have liked. Life will

be easier if you share these frustrations with your family and friends more openly.

You have to face life as bravely as you can and achieve as much as you can by your own efforts.

Ultimately, you have done so much and you will feel proud of yourself and your achievements.

Dr Alan Baum

Andy is a driver for all-disabled racing team, Team BRIT. Andrew was riding his motorbike in 2013 when a car collided with him, causing a range of serious injuries. He tore the ACL in his knee, which required partial reconstruction, he has an inverted right ankle, muscle damage to his lower leg and a large piece of muscle had to be removed from the back of his calf. He also has limited movement and deformity in his right shoulder, trapped nerves in his neck, scoliosis and spondylitis in his spine and a deformed right hand and foot. Alongside the physical damage, Andrew suffers with post-traumatic stress disorder, depression and anxiety. In September 2019 he was invited to become a rookie driver with the team and currently competes in a BMW 116 in the Britcar Championship, securing three podium positions in his first year.

Dear Andy,

I'm writing to you as a very different person to who you are now. I wouldn't want you to know all the details of the life that is ahead of you – life is full of surprises that we shouldn't try to prepare for – but I do want to give you some words of advice to help you make the most of the opportunities you will be given, and to help you cope with some of the tougher times.

I know already, life hasn't been easy. You may not have the 'normal' family set-up that a lot of people around you have – but remember that your mum and dad chose you – which makes you pretty special. You're unique – you break the mould – and that's certainly something to be proud of. Not everyone will see it like that, and you'll sometimes get a hard time from some kids at school – but just remember how loved you are.

Hold your head up high and hang in there. A lot of the tough things we face as kids feel

overwhelming at the time, but I promise you I now look back and see them as nothing more than a bump in the road. There's going to be some pretty big bumps and you'll need to re-design your life after an accident which will change a lot of things, but you'll learn to adapt, and everything will come together. There'll be as many highs as lows – you're going to have an amazing life filled with excitement, fun, opportunity and adventure. You never know what's just round the corner.

Never forget your dreams – you know how much you're enjoying karting right now? Stick with it because it's going to set the foundations for a career in motorsport with the most incredible team of inspirational people who have all faced challenges similar to you. So for now, stay strong, keep positive, believe and you will achieve.

Andrew

Andy Tucker, Racing Driver



Photo: Darren Cook

There'll be as many highs as lows - you're going to have an amazing life filled with excitement, fun, opportunity and adventure.

Dr Hamied Haroon, Scientist



**Keep it fun, keep it enjoyable.
You will find fulfillment.**

Dr Hamied Haroon is a Research Scientist at The University of Manchester (UoM), having gained his PhD there in 2005 in biomedical MR imaging. He was elected chair of the University's Disabled Staff Network (DSN) when it was established in 2007, with its first proud success to achieve dedicated support for disabled staff! Hamied launched the National Association of Disabled Staff Networks (NADSN) in 2014 at the ground-breaking "What Are We Hiding?" national conference that he and Melanie Sharpe organised together at UoM. Hamied currently chairs NADSN, a "super-network" to connect and represent DSNs in universities, NHS Trusts and other sectors.

Dear younger Hamied,

Don't be worried about failure or people trying to put you off things.

Continue with your passion for science. The way things will work out are better than you could have hoped for.

You'll initially think you want to be a doctor but the careers advice at school will tell you not to follow that path because you are disabled. You will eventually discover a medical physics book and realise that there is a different way to get into medicine, not as a medical doctor but as a medical physicist. By taking that path, you'll enjoy doing what you do even more than if you had become a medical doctor.

You will get to work with doctors and scientists and all sorts of extraordinary people. What you're doing now is way more fun!

Don't be disheartened when people try to put you off your aspirations and dreams - don't give up, just keep at it. And when someone suggests you should do something different, even your mother, don't go that way because you're never going to be satisfied as you will no longer be following your passion or dream. Go along the more exciting path. Be like Roald Dahl and his books! His characters always challenge the status quo and the system and that's the kind of thing you have to do to make change and once you make change it's changed for other people as well. You will face some struggles at university studying physics but continue to push the boundaries and push things forward to make a difference.

Keep it fun, keep it enjoyable. You will find fulfilment.

Hamied

Thank you for reading. We hope that these stories and letters provide some inspiration for you.

It may seem daunting now, but having a strong network around you, people you trust and who have your back, will help no end.

Thank you to the celebrities, professionals, and sportspeople who took time to write and share a letter to their younger self, to the families and young people who provided stories and to our network of 82 Roald Dahl Specialist Nurses who support over 21,000 children and young people across the UK.

You can help us to establish more **Roald Dahl Transition Specialist Nurses** in the NHS. Donate what you can, from a **phizz-whizzing fiver** to a **fantabulous fifty**, and help seriously ill children and young people lead a more marvellous life.

roalddahlcharity.org/donate

For more information:

For more information about how to get involved, please contact:

fundraising@roalddahlcharity.org

and for press enquiries, please contact: press@roalddahlcharity.org

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Roald Dahl's Marvellous Children's Charity uses a pump-priming model and raises funds for the first two years of the Roald Dahl Specialist Nurse's salary and the NHS funds thereafter. This has been a successful model with almost all Roald Dahl Specialist Nurse posts retained since the charity started establishing nurses in 1992.

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