



University of Dundee

Neurology Specific Principles of Good Transitions

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NEUROLOGY SPECIFIC PRINCIPLES OF GOOD TRANSITIONS



**PREPARING FOR THEIR DEVELOPMENT
ACROSS THE LIFESPAN**

NEUROLOGY SPECIFIC PRINCIPLES OF GOOD TRANSITIONS:

Preparing for their development across the lifespan

The aim of this study was to understand transitions across the life span for people living with a neurological condition. Data were collected using semi-structured interviews and assistive technologies. The comics are based on our interpretation of some of that data.

Research Team

Stephanie Fraser
Dr Jenny Preston
Rebecca Williams
Professor Divya Jindal-Snape
Dr Jane Green

Thanks to all the participants for giving us valuable insights into their multiple and multi-dimensional transition experiences.

This study and comic anthology were funded by the Scottish Government Neurological Framework Implementation Fund.



cerebral
palsy
scotland



Scottish Government
Riaghaltas na h-Alba
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University
of Dundee

School of Humanities, Social
Sciences and Law
Transformative Change: Educational and
Life Transitions (TCELT) Research Centre



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Lettering: Damon Herd.

Editors: Divya Jindal-Snape, Jenny Preston and Stephanie Fraser.
Cover art by Tasha Leah Santiago; Production: Damon Herd.

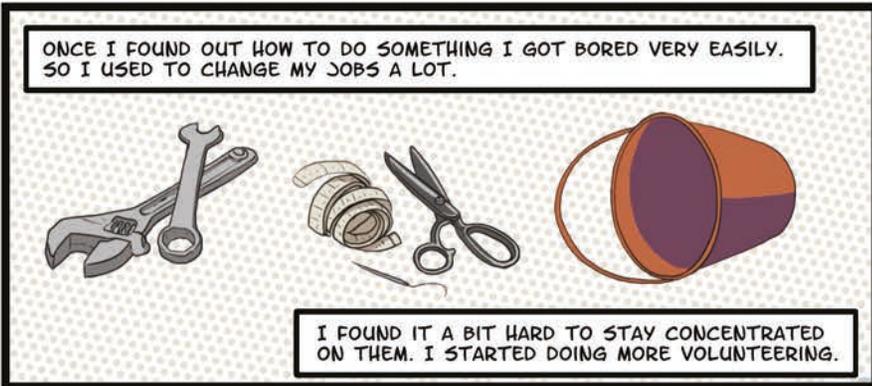
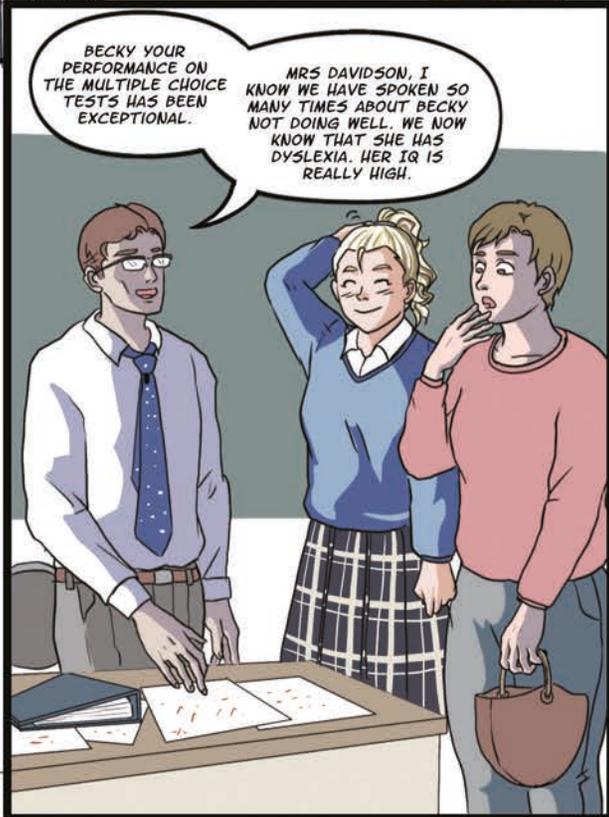
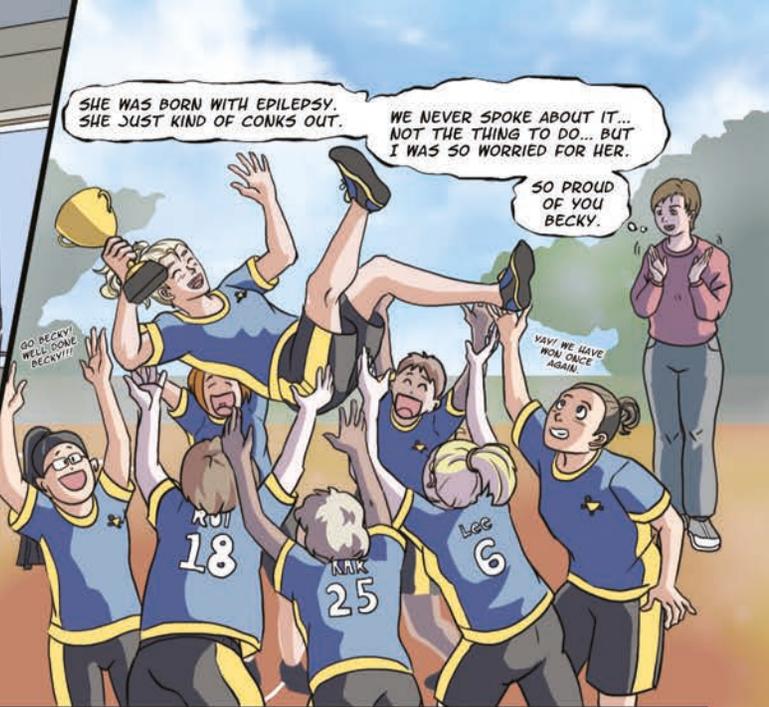
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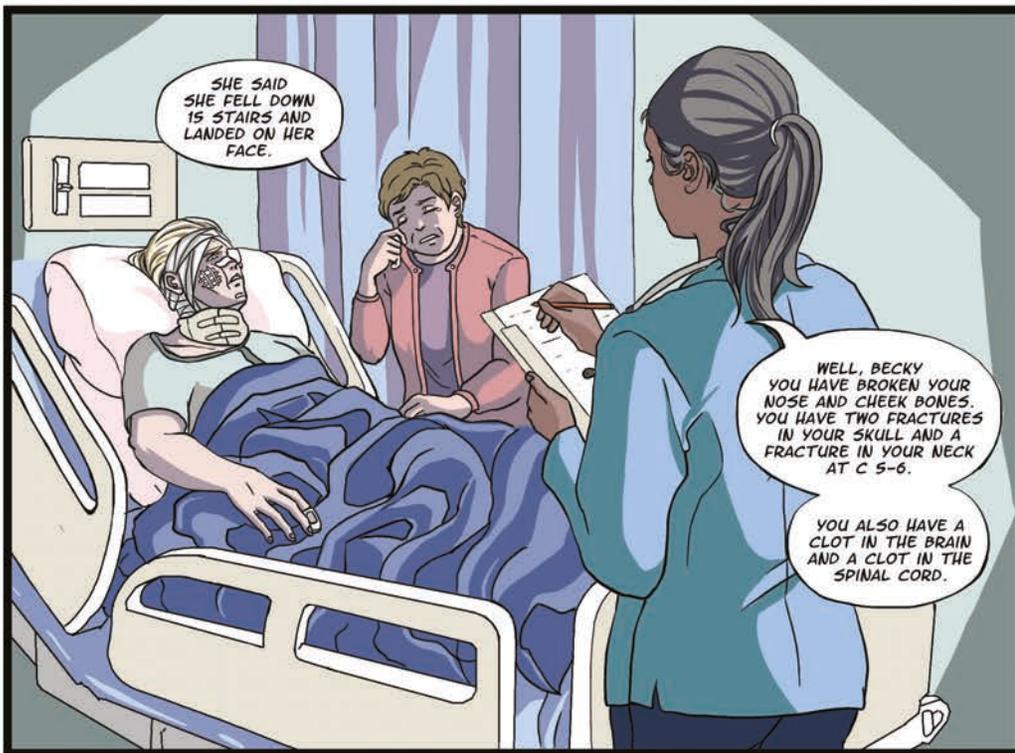
ACCEPTING ME, ACCEPTING YOU:

Multiple life transitions due to neurological conditions



Script: Divya Jindal-Snape, Jane Green and Jenny Preston.
Art and lettering: Clio Ding.

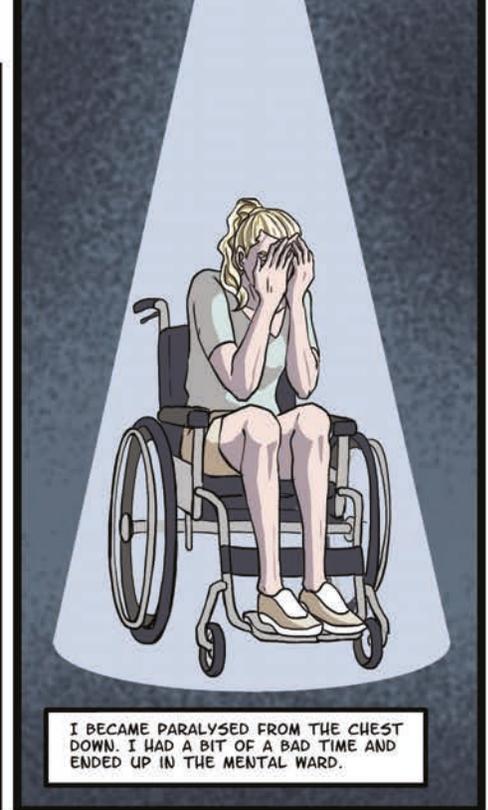




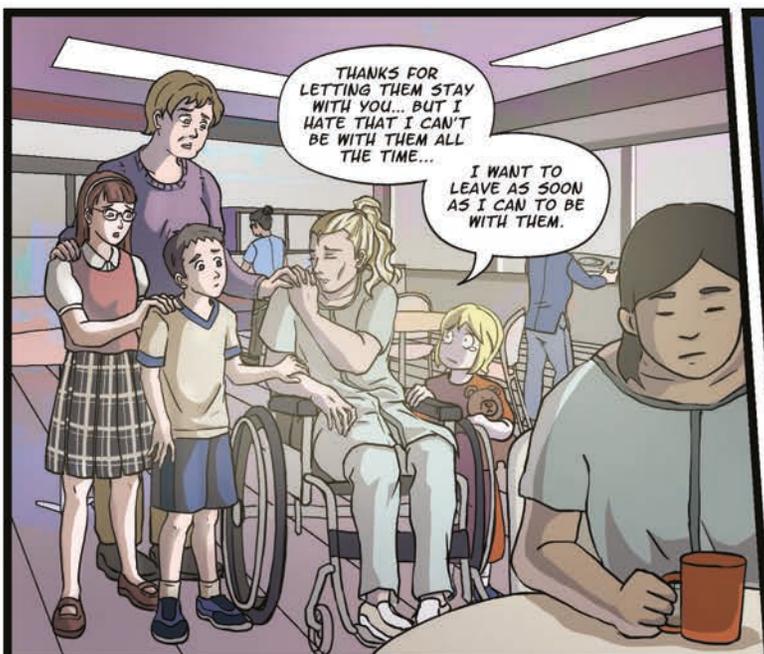
SHE SAID SHE FELL DOWN 15 STAIRS AND LANDED ON HER FACE.

WELL, BECKY YOU HAVE BROKEN YOUR NOSE AND CHEEK BONES. YOU HAVE TWO FRACTURES IN YOUR SKULL AND A FRACTURE IN YOUR NECK AT C 5-6.

YOU ALSO HAVE A CLOT IN THE BRAIN AND A CLOT IN THE SPINAL CORD.



I BECAME PARALYSED FROM THE CHEST DOWN. I HAD A BIT OF A BAD TIME AND ENDED UP IN THE MENTAL WARD.



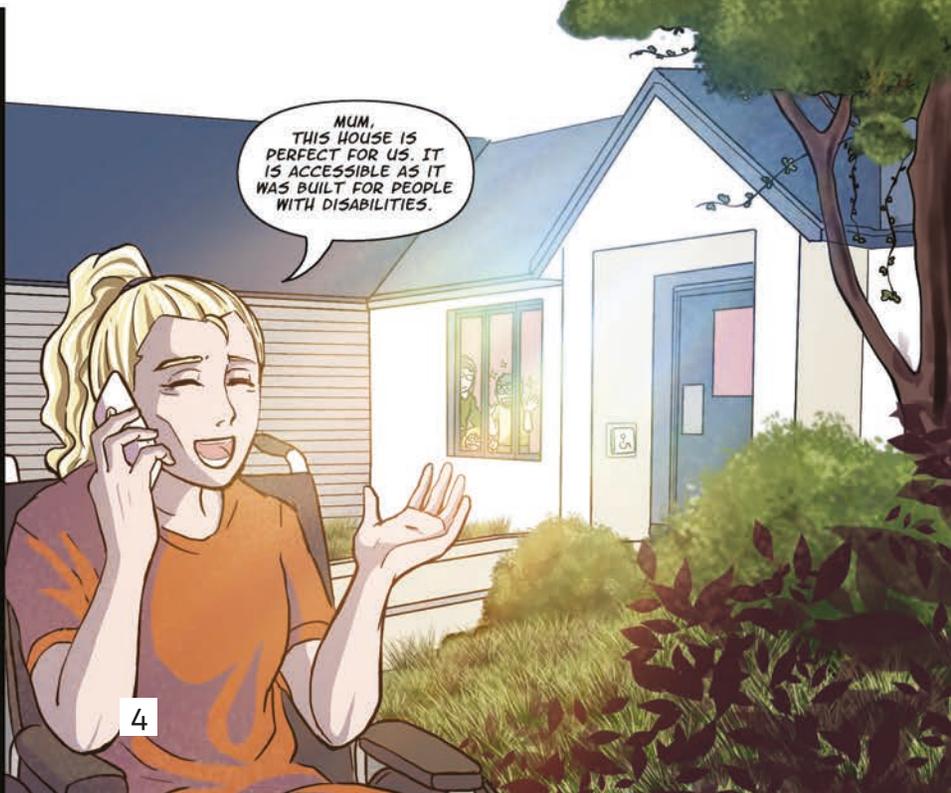
THANKS FOR LETTING THEM STAY WITH YOU... BUT I HATE THAT I CAN'T BE WITH THEM ALL THE TIME...

I WANT TO LEAVE AS SOON AS I CAN TO BE WITH THEM.

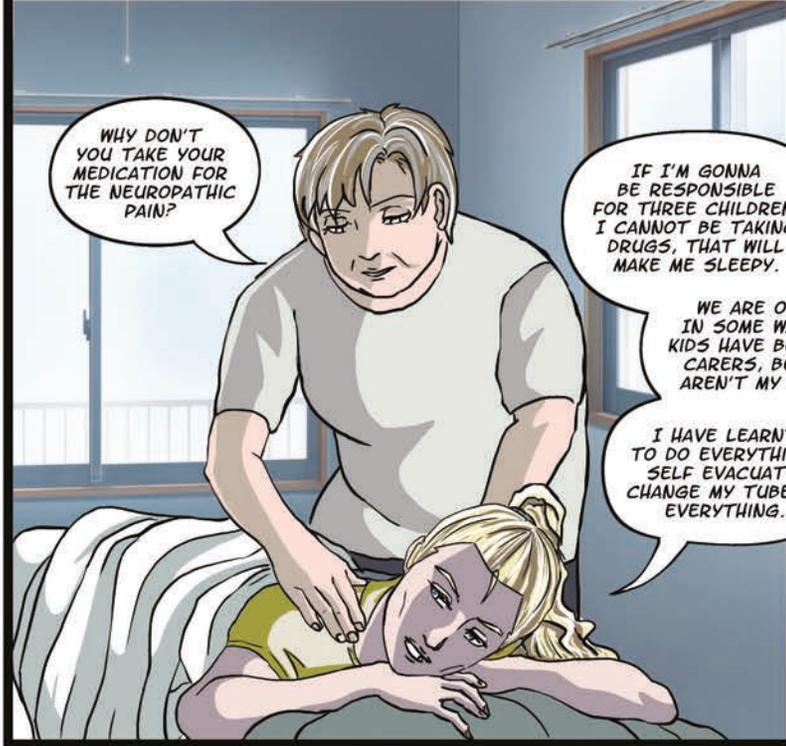


WELL... I THINK THE EASIEST IS FOR US TO MOVE INTO THE HOMELESS UNIT.

'CAUSE THAT IS THE ONLY WAY I AM GOING TO GET A HOUSE QUICKER.



MUM, THIS HOUSE IS PERFECT FOR US. IT IS ACCESSIBLE AS IT WAS BUILT FOR PEOPLE WITH DISABILITIES.

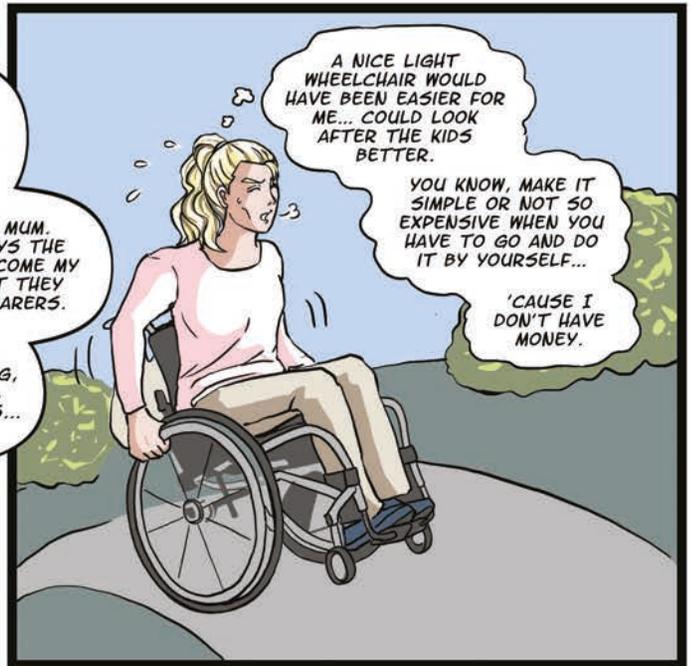


WHY DON'T YOU TAKE YOUR MEDICATION FOR THE NEUROPATHIC PAIN?

IF I'M GONNA BE RESPONSIBLE FOR THREE CHILDREN, I CANNOT BE TAKING DRUGS, THAT WILL MAKE ME SLEEPY.

WE ARE OK MUM. IN SOME WAYS THE KIDS HAVE BECOME MY CARERS, BUT THEY AREN'T MY CARERS.

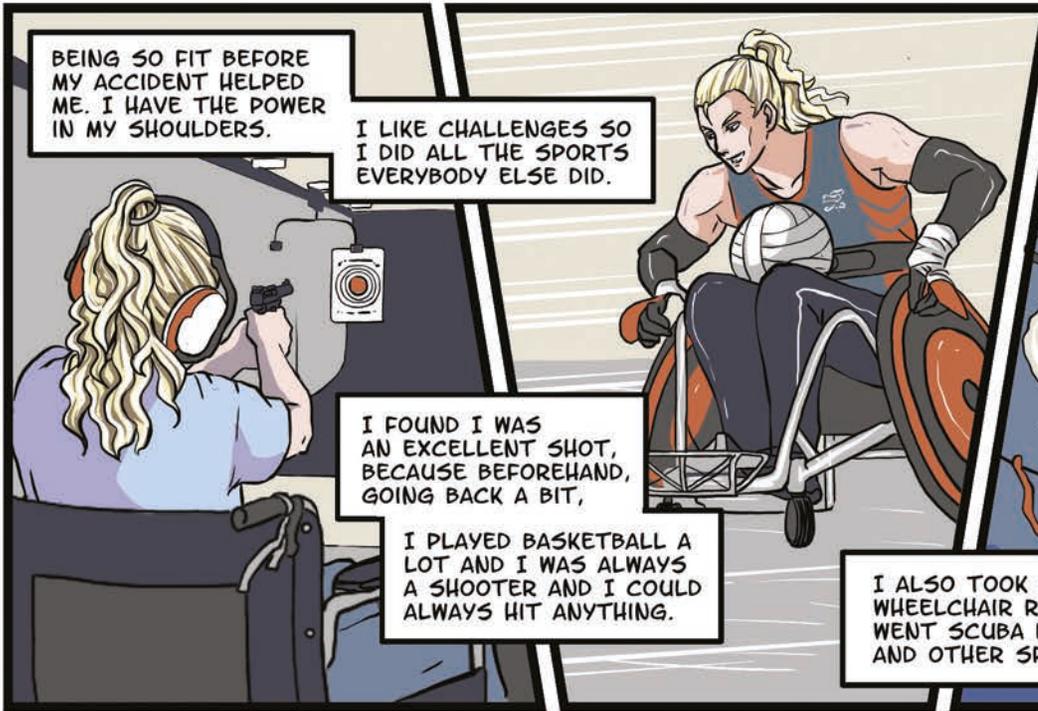
I HAVE LEARNT TO DO EVERYTHING, SELF EVACUATE, CHANGE MY TUBES... EVERYTHING.



A NICE LIGHT WHEELCHAIR WOULD HAVE BEEN EASIER FOR ME... COULD LOOK AFTER THE KIDS BETTER.

YOU KNOW, MAKE IT SIMPLE OR NOT SO EXPENSIVE WHEN YOU HAVE TO GO AND DO IT BY YOURSELF...

'CAUSE I DON'T HAVE MONEY.



BEING SO FIT BEFORE MY ACCIDENT HELPED ME. I HAVE THE POWER IN MY SHOULDERS.

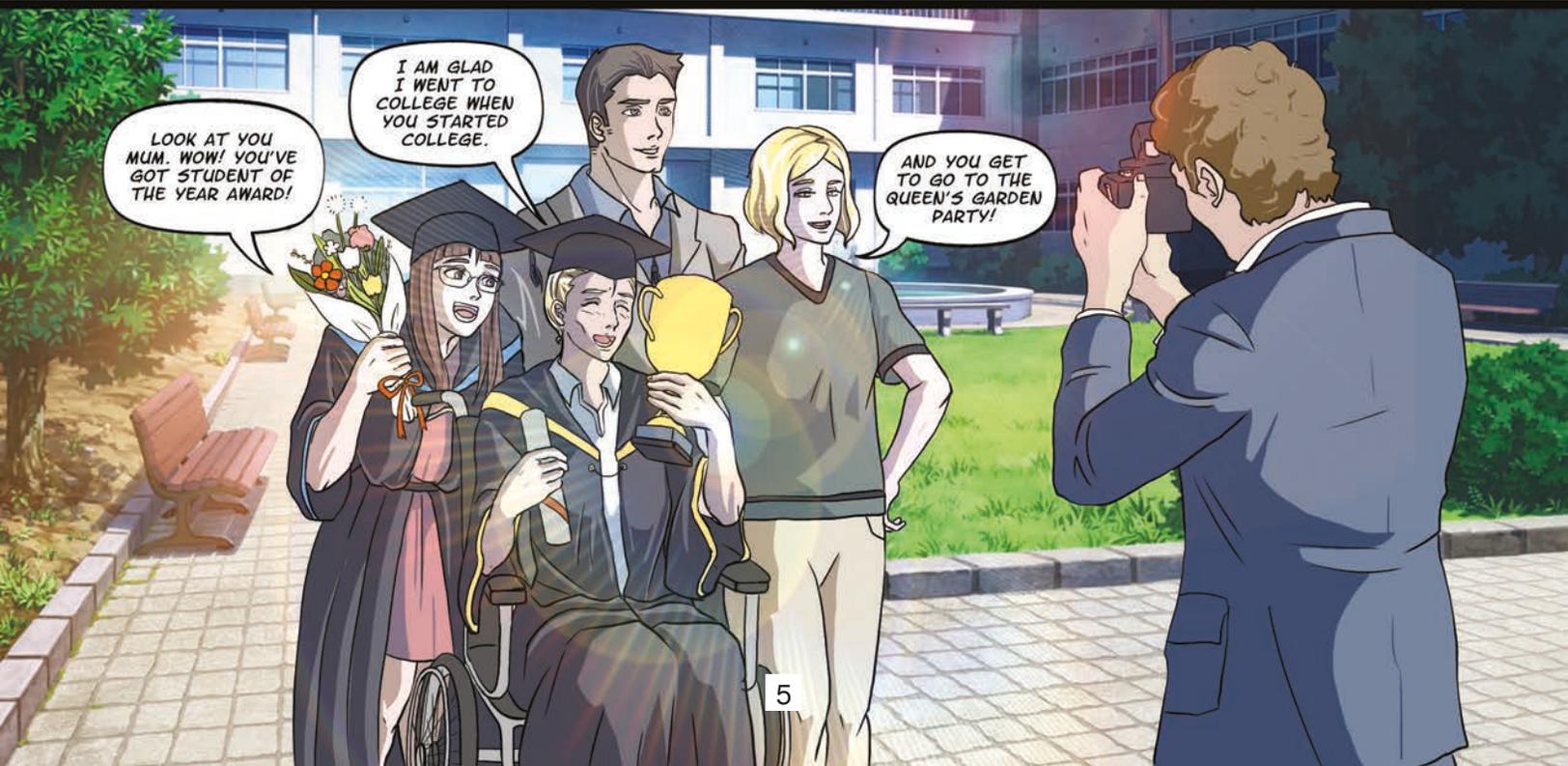
I LIKE CHALLENGES SO I DID ALL THE SPORTS EVERYBODY ELSE DID.

I FOUND I WAS AN EXCELLENT SHOT, BECAUSE BEFOREHAND, GOING BACK A BIT,

I PLAYED BASKETBALL A LOT AND I WAS ALWAYS A SHOOTER AND I COULD ALWAYS HIT ANYTHING.



I ALSO TOOK UP WHEELCHAIR RUGBY. AND WENT SCUBA DIVING... AND OTHER SPORTS...



LOOK AT YOU MUM. WOW! YOU'VE GOT STUDENT OF THE YEAR AWARD!

I AM GLAD I WENT TO COLLEGE WHEN YOU STARTED COLLEGE.

AND YOU GET TO GO TO THE QUEEN'S GARDEN PARTY!

MY BIGGEST TRANSITION WAS THAT I HAD TO LEARN HOW TO ADAPT TO MY BODY.

INSTEAD OF THINKING WHAT I USED TO DO, IT'S TRYING TO ACHIEVE WHAT I CAN DO WITH WHAT I'VE GOT.

YOU WERE GOOD AT ADAPTING AT SCHOOL TOO.

THANKS. ALL MY EXPERIENCES HAVE HELPED DEVELOP MY RESILIENCE.

YOU LOOK GREAT BY THE WAY.

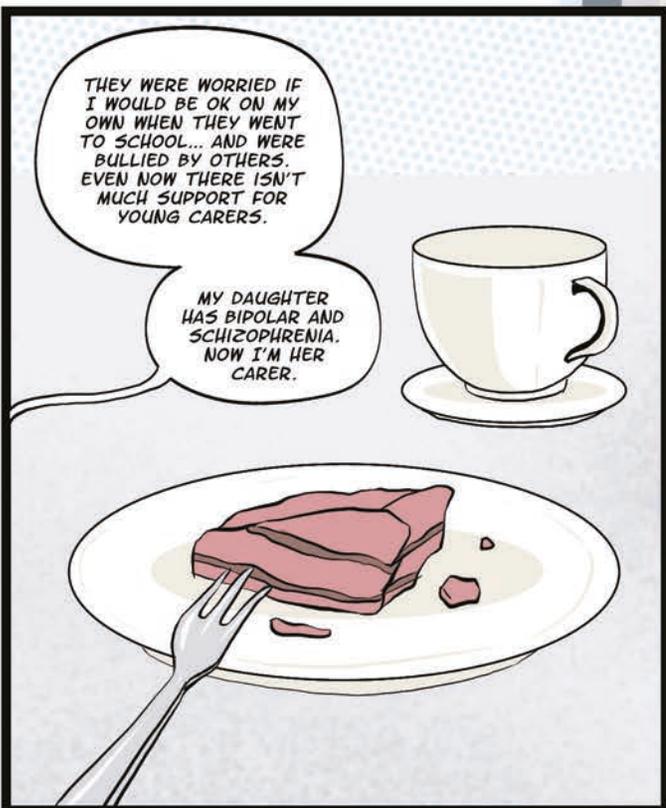
YOU KNOW, MY BODY HASN'T SEEN A SHOWER IN 20 YEARS! WHAT WOULD I DO WITHOUT BABY WIPES, EH?!



HOW ARE THE KIDS DOING? THEY ARE ALL GROWN UP!

THEY ARE GREAT KIDS.

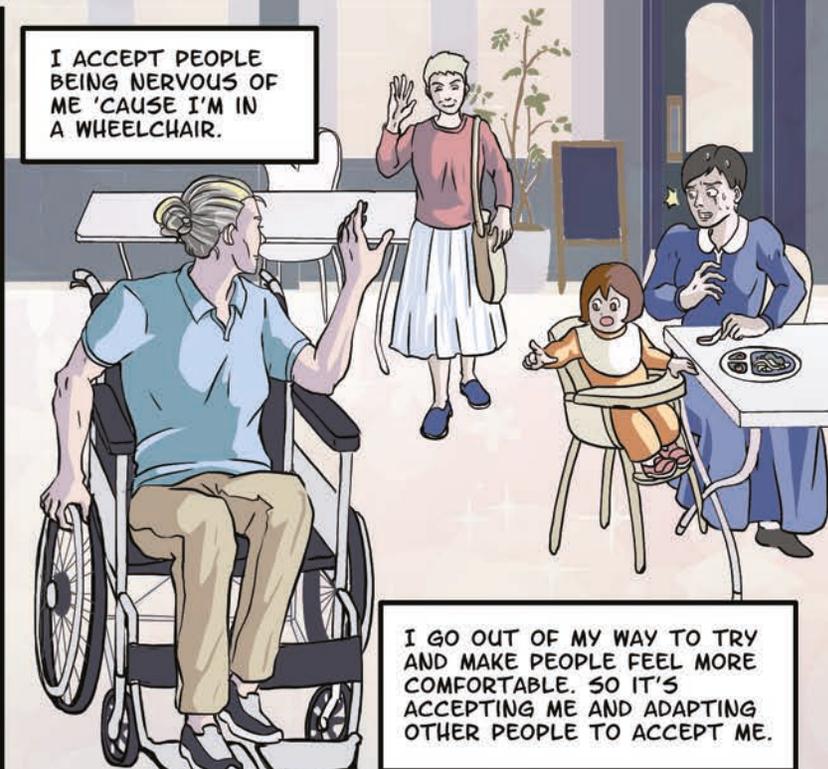
THEY ARE! MY INJURY HAD A MASSIVE IMPACT ON THEM WHEN THEY WERE LITTLE.



THEY WERE WORRIED IF I WOULD BE OK ON MY OWN WHEN THEY WENT TO SCHOOL... AND WERE BULLIED BY OTHERS. EVEN NOW THERE ISN'T MUCH SUPPORT FOR YOUNG CARERS.

MY DAUGHTER HAS BIPOLAR AND SCHIZOPHRENIA. NOW I'M HER CARER.

I ACCEPT PEOPLE BEING NERVOUS OF ME 'CAUSE I'M IN A WHEELCHAIR.



I GO OUT OF MY WAY TO TRY AND MAKE PEOPLE FEEL MORE COMFORTABLE. SO IT'S ACCEPTING ME AND ADAPTING OTHER PEOPLE TO ACCEPT ME.

MULTIPLE EDUCATIONAL and LIFE TRANSITIONS:

AGED 3

LIZZY HAS HAD CEREBRAL PALSY SINCE BIRTH. IT HAS AFFECTED HER MOVEMENT, MOBILITY AND SPEECH.

DID YOU HAVE GOOD SUPPORT FROM ANY ORGANISATIONS?

NOT WHEN SHE WAS BORN. WHEN SHE WAS AROUND ONE YEAR OLD A CEREBRAL PALSY CHARITY OPENED.

THEY HAD SPECIALIST PHYSIOTHERAPISTS WHO ALSO HELPED HER LEARN ABOUT DIFFERENT TEXTURES AS SHE COULDN'T PLAY WITH TOYS OR SAND.

I THINK THIS ADDITIONAL SUPPORT NEEDS NURSERY IS GREAT. IT IS GIVING THEM A GREAT START INTO THE OUTSIDE WORLD.

AGED 6

ARE YOU EXCITED THAT YOU WILL BE GETTING YOUR SPEECH DEVICE SOON?

AGED 12

THANKS SO MUCH FOR GIVING US THREE INDUCTION DAYS. LIZZY WAS A BIT NERVOUS ABOUT STARTING HIGH SCHOOL BUT THIS HAS REALLY HELPED HER.

OUR PLEASURE. LIZZY, WHY DON'T WE GO TO THE CLASSROOM WHERE ALL YOUR EQUIPMENT WILL BE MOVED WHEN YOU START HERE?

AGED 17

LIZZY HAS DONE WELL AT SCHOOL AND WANTS TO GO TO COLLEGE NEXT. WE WOULD LIKE TO FIND OUT HOW DIFFERENT SERVICES CAN SUPPORT HER.

HI LIZZY, I'M A SOCIAL WORKER. AS YOU ARE MOVING TO COLLEGE, YOU MIGHT NEED A PERSONAL ASSISTANT AND I WILL WORK WITH YOU TO SELECT ONE.

AGED 21

I MET WITH A SOCIAL WORKER AND WE DISCUSSED MY NEEDS.

SHE ALLOCATED ME CARE HOURS AND THEN FOUND ME A CARE COMPANY.

AFTER FOUR YEARS HERE I AM READY TO TRANSITION TO A MAINSTREAM COMPUTING COURSE.

AGED 26

I HAVE BEEN VOLUNTEERING WITH TWO CHARITIES. I WRITE BLOGS, DESIGN GRAPHICS AND MANAGE SOCIAL MEDIA FOR THEM.

I AM A COLLAGE ARTIST IN MY SPARE TIME.

I HAVE MADE FOUR LARGE COLLAGES AND TWENTY-ONE MINI COLLAGES.

IT ISN'T EASY DUE TO MY HAND MOVEMENTS BUT I AM NOT GOING TO LET CEREBRAL PALSY STOP ME FROM DOING WHAT I LOVE!





I FELT LIKE I HAD FULL SUPPORT FROM SCHOOL AND COLLEGE WHEN I WAS MOVING ONTO SOMETHING NEW. I HAD MEETINGS AND WAS ALWAYS GIVEN A CHOICE OF WHAT I WANTED TO DO WITH MY FUTURE.



WHEN I WAS COMING UP FOR 18, I HAD TO TRANSITION FROM PAEDIATRICS TO ADULT SERVICES, WHICH MEANT I HAD TO GET A SOCIAL WORKER. IT WAS A LONG PROCESS BUT I HAD A CARE PLAN IN PLACE FOR STARTING COLLEGE.

THE BIGGEST TRANSITION I EXPERIENCED WAS WHEN I WENT TO DO A MAINSTREAM COURSE STUDYING ADMIN AND COMPUTING.

I DID REALLY WELL!



THROUGHOUT MY EDUCATION, A TEACHER OR LECTURER WAS ALWAYS THERE TO SUPPORT ME.

I HAD LOTS OF FRIENDS AT SCHOOL WHOM I GREW UP WITH. WHEN I MOVED TO COLLEGE, I NEVER GOT TO SEE VERY MANY FRIENDS APART FROM MY BEST FRIENDS WHO I AM STILL IN TOUCH WITH TODAY BUT THAT'S JUST WHAT HAPPENS IN LIFE.

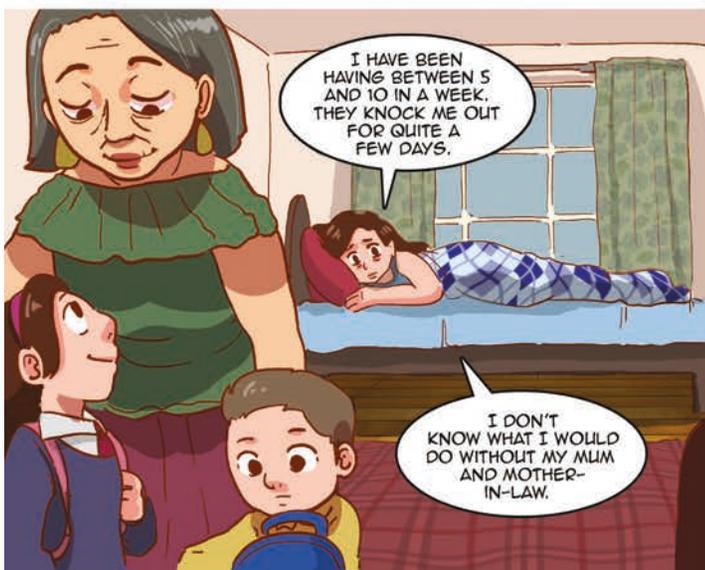
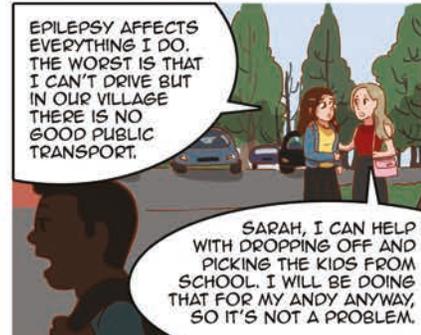


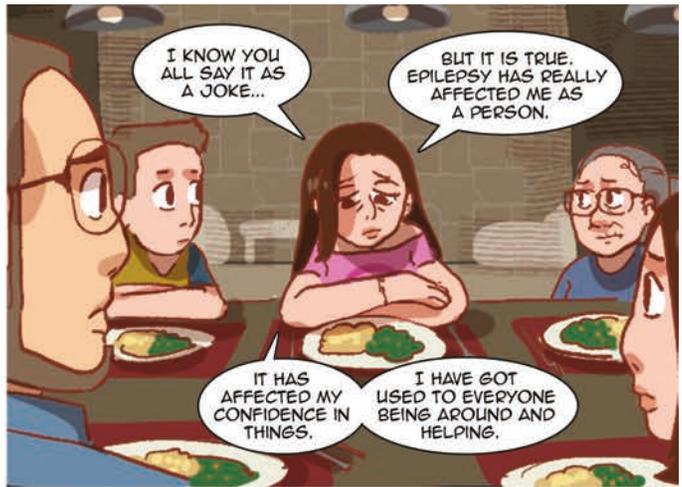
I AM GOING TO HAVE A VERY BIG TRANSITION IN THE NEAR FUTURE AS I AM MOVING HOUSE. THE HOUSE I HAVE LIVED IN ALL MY LIFE IS NO LONGER SUITABLE FOR MY NEEDS.

MY HOPES ARE TO GET A SUITABLE HOUSE. I WILL HAVE MY OWN SPACE WHICH MEANS I WILL BE ABLE TO GET SUPPORT FROM SOCIAL SERVICES WITHOUT RELYING ON MY FAMILY 24/7.

MULTIPLE AND MULTI-DIMENSIONAL TRANSITIONS: DEVELOPING A NEUROLOGICAL CONDITION AS AN ADULT

Script: Divya Jindal-Snape, Jane Green and Jenny Preston; Art: Tasha Leah Santiago; Lettering: Damon Herd.





I WANT TO START A SERVICE FOR PEOPLE LIVING WITH EPILEPSY IN MY AREA.

I WANT TO HELP WITH PSYCHOSOCIAL EFFECTS OF EPILEPSY RATHER THAN THE MEDICAL ONES. I CAN DO CLINICAL LIAISON. IF WE CAN GET IN TOUCH WITH THOSE TREATING THEM.

THINGS THAT MIGHT HAVE HELPED ME, SUCH AS PAIRING WITH OTHERS WHO HAVE EPILEPSY, SET UP A CHARITY HELPLINE, AND SHARING RESEARCH IN AN ACCESSIBLE MANNER.

CONTRIBUTOR BIOGRAPHIES

Monica Burns is a comic artist based in Aberdeen, Scotland. They graduated from the MLitt in Comics and Graphic Novels with the University of Dundee in 2017. You can find their work on Instagram at @thren_art

Clio Ding is a Singaporean art educator and a comics nerd who dabbles with making comics and writing about them when not occupied with food.

Stephanie Fraser is CEO of Cerebral Palsy Scotland. Cerebral Palsy Scotland is a charity that improves the lives of children and adults with cerebral palsy through specialist therapy, support and information.

Dr Jane Green is a part-time researcher with Cerebral Palsy Scotland. She was previously a senior lecturer in the School of Health and Life Sciences at Glasgow Caledonian University.

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Dr Jenny Preston is a Consultant Occupational Therapist with almost 40 years' experience within the field of neurological rehabilitation including the development and delivery of person-centred programmes of care while contributing to the evidence base within this field through academic and research practice.

Tasha Leah Santiago is a digital animation student currently studying at Singapore Polytechnic, who also creates local comics for CS comics, a Singaporean superhero franchise.

Rebecca Williams is a Policy and Development Worker with ARC Scotland and the Scottish Transitions Forum, a national network committed to improving the experiences of young people (14 to 25 years) who require additional support and who are making the transition to young adult life.



FACT SHEET

The **World Health Organization (WHO)** (2016) defines neurological conditions as diseases of the central and peripheral nervous system, i.e., the brain, spinal cord, cranial nerves, peripheral nerves, nerve roots, autonomic nervous system, neuromuscular junction, and muscles. Full definition is available at Annex B Definition of Neurological Conditions - Neurological care and support: framework for action 2020-2025 - gov.scot at the following link:

<https://www.gov.scot/publications/neurological-care-support-scotland-framework-action-2020-2025/pages/7/>

- Neurological conditions affect the brain, spinal cord, nerves and muscles.
- There is a wide range of neurological conditions, and they can affect people in very different ways. Some neurological conditions are present from birth such as cerebral palsy while others may develop at a later stage in life - from childhood to old age.
- Some conditions are hereditary, such as Huntington's disease
- Some conditions are caused by acute problems such as infections (for example, meningitis).
- The cause of many neurological conditions remains uncertain.
- Some neurological conditions are very common but some are extremely rare.
- Most neurological conditions affect people's quality of life and some will cause life-long loss of function.
- While some conditions can be treated, other conditions need to be managed as they progress or managed as long-term conditions, and other conditions can be progressive or terminal.
- It is important that people affected by a neurological condition receive the right care and treatment at the right time.

You can access the Scottish Government's framework and action plan here:
<https://www.gov.scot/publications/neurological-care-support-scotland-framework-action-2020-2025/>

Further information about neurological conditions can be found here
Neurological conditions - Illnesses and long-term conditions:
<https://www.gov.scot/policies/illnesses-and-long-term-conditions/neurological-conditions/>

What is a neurological condition? | Neurological Alliance of Scotland:
<https://www.scottishneurological.org.uk/neurological-conditions/>

<https://cerebralpalsyscotland.org.uk/>

You can access 'Principles of Good Transitions 3' here:
<https://scottishtransitions.org.uk/summary-download/>