

“So... what happens now?”

The process of transition from child services to adult hospice services and supportive palliative care

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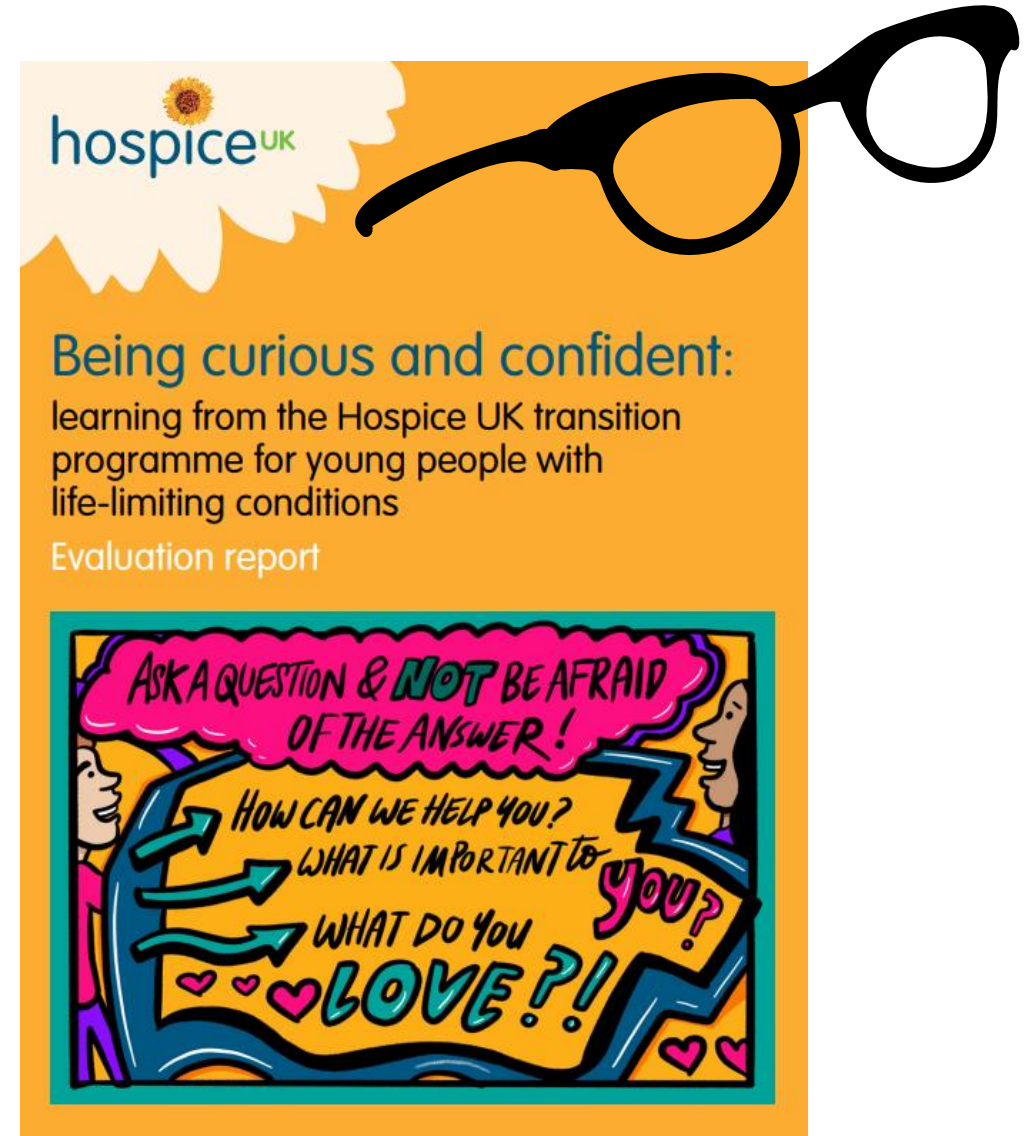


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Overview

- Alex
- What is Transition?
- Who should care?
- Our role @ PPWH
- Success
- A personal relection



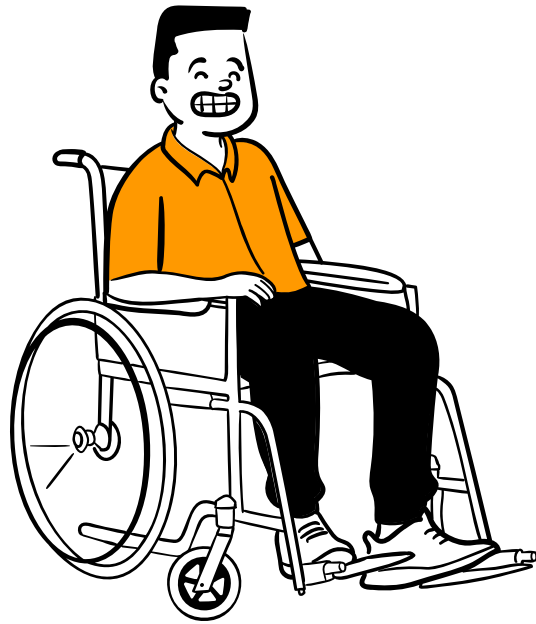
Being curious and confident:

learning from the Hospice UK transition programme for young people with life-limiting conditions

Evaluation report



Alex



Alex, what does a good day look like for you ?

“When I’m happy, out with friends, playing football. I like a good meal too and a trip to the cinema. When I’m healthy...”

What does a hard day look like for you?

“When I’m in pain, lonely, not sleeping. When my equipment’s not working. When my carers cancel and my parents are just done in...”

Leslie & Mackenzie

“Since children’s services ended, we as a family have not had any support...”



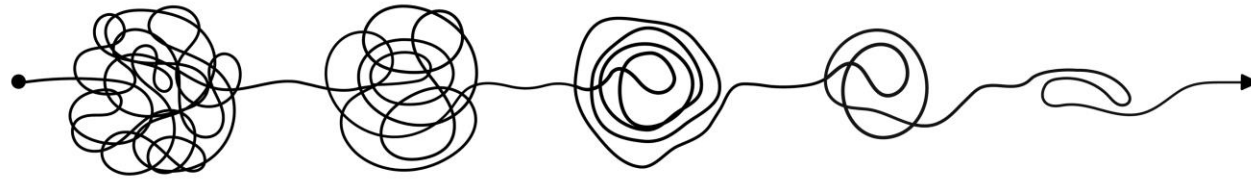
Mackenzie:

“I want to care for him at home but think that I’d need back up... I’m not sure that I am brave enough to care for him (at the end of his life)... but hope that I can focus on being his parent and be with him...”

Leslie:

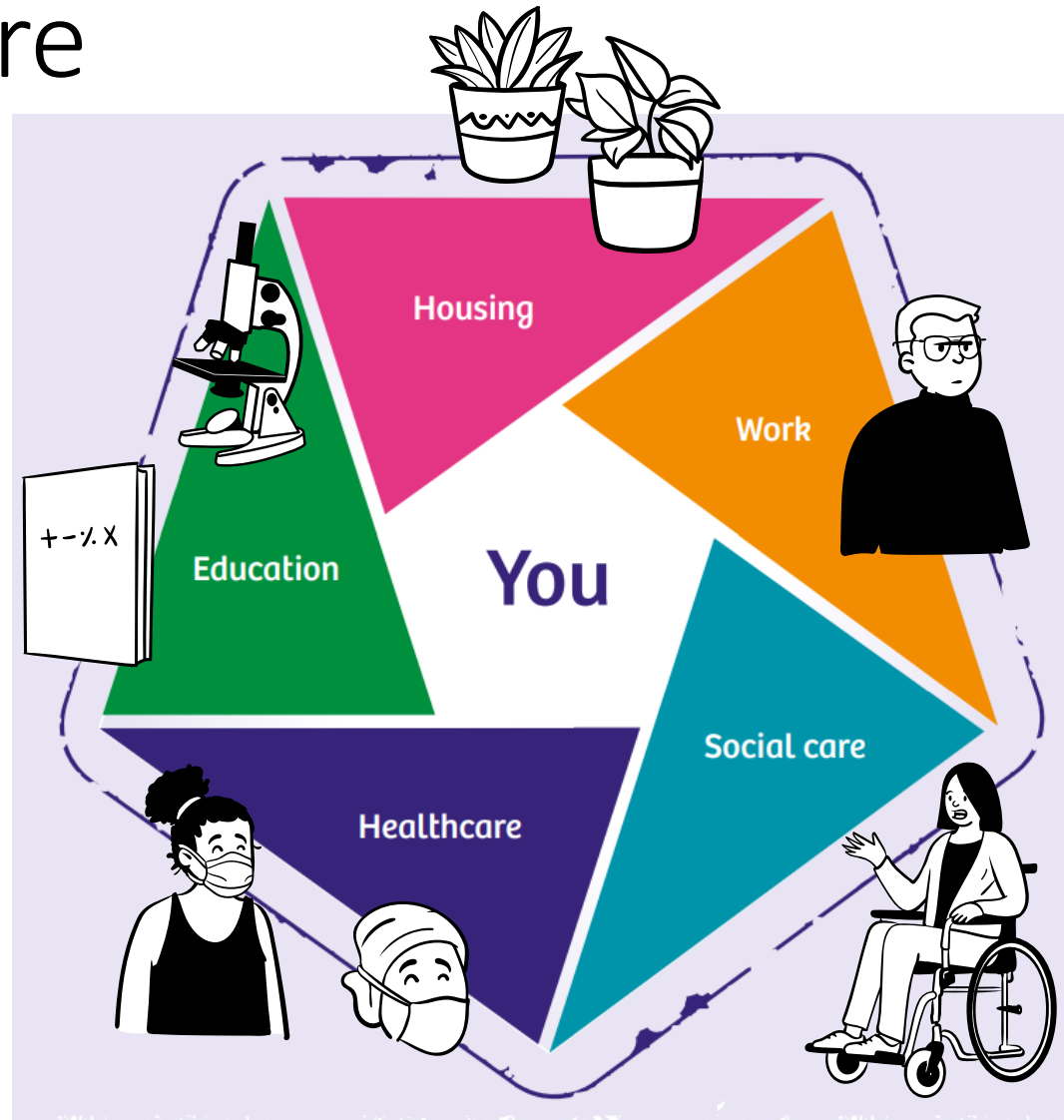
“We feel unsupported since leaving paediatric services... I feel that people have given up on Alex... I feel that I can’t go out and leave them, I’m worried... we’re so alone...”

Transition



'Transition' describes the purposeful and planned process of supporting young people to move from children's to adults' services. The process should support children and young people's medical, psychosocial, educational and vocational needs.

Holistic care



Who should care?

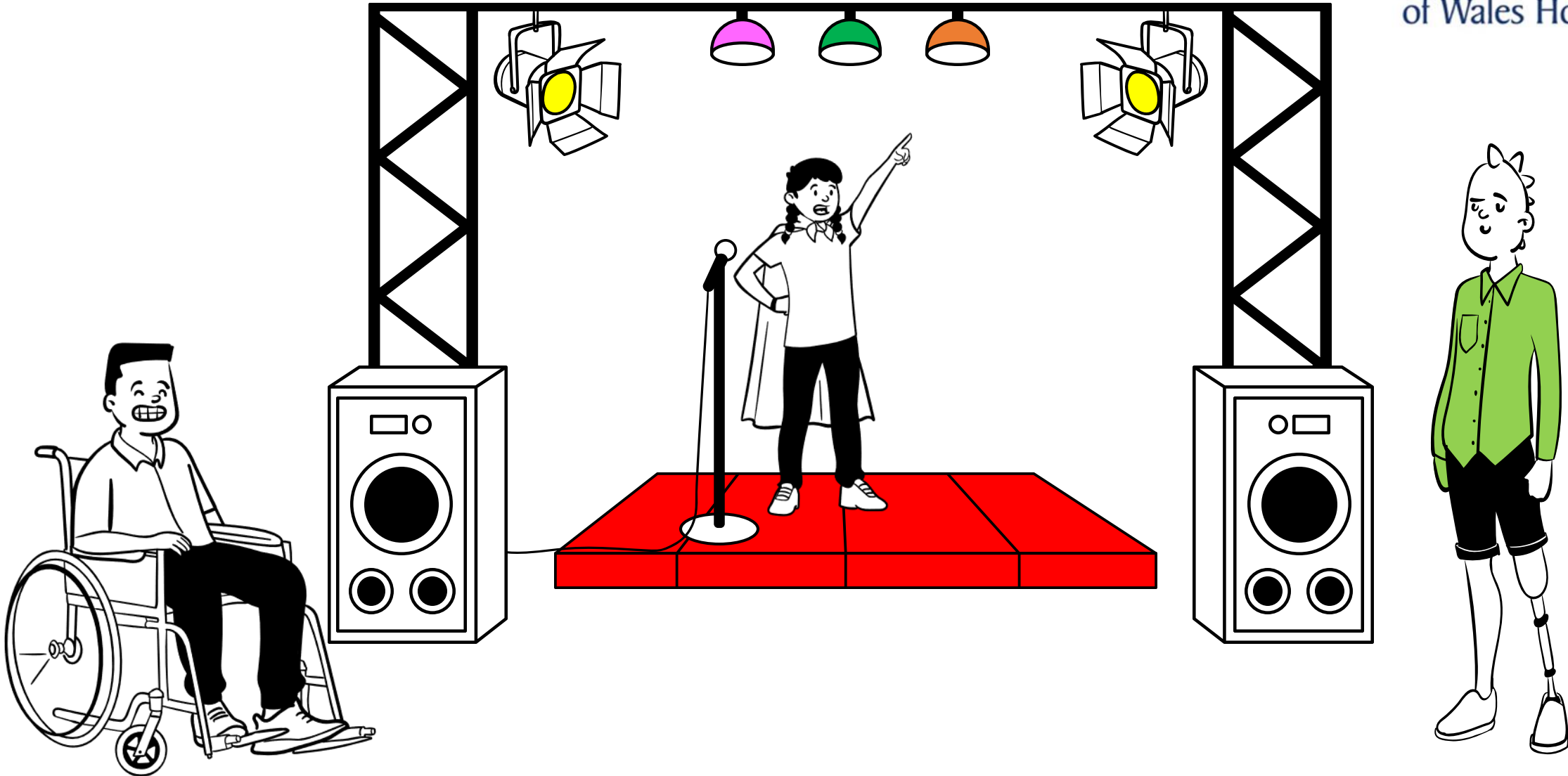
“an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness.”

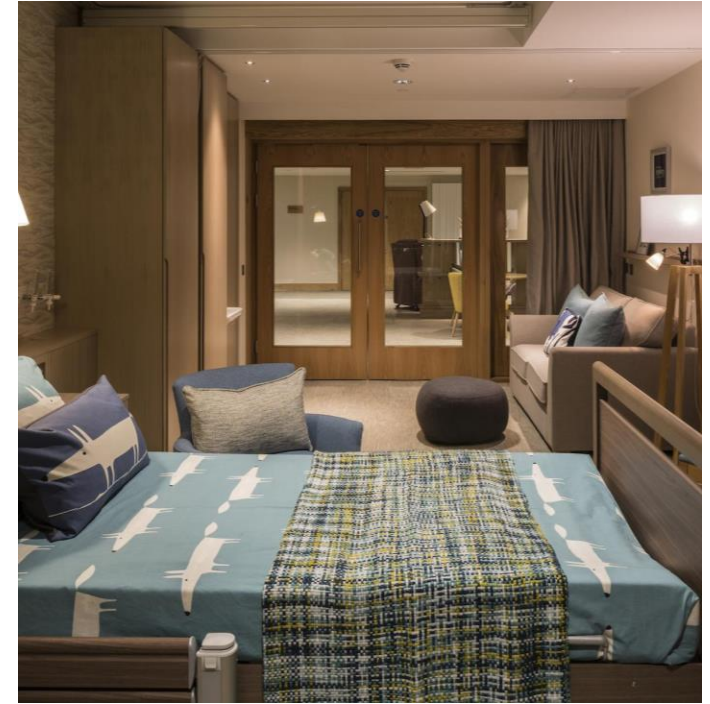


Our role at PPWH



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“a safe, accessible, age-appropriate environment...”



To help the YA feel confident about the help they are getting and feel safe or safer.

To ensure the YA feels listened to carefully and that their wishes have been heard and understood.

To encourage the YA to be involved in discussions and decisions that affect them.

To support the YA in their understanding of what is happening and why.

To enable the YA to take control, make decisions and live a healthier life.

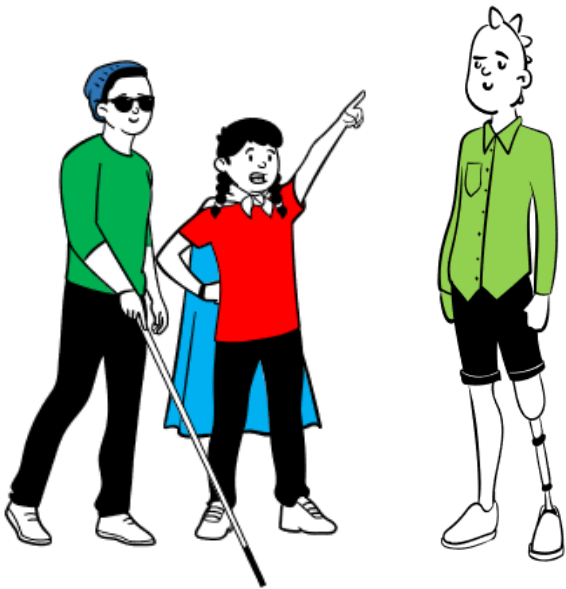
To establish that the YA knows where to find appropriate help and that it is available as soon as possible.

To develop a coordinated response from all professionals involved in the care of the YA.



Who are the Young Adults?

chronic
dysplasia CMV learning
progressive ullrich
injury telangiectasia
congenital renal
palsy neuro-genetic angelman
ataxia disease cardiac
acquired undiagnosed brain
duchenne condition
fibrous disability



Starting the journey

Coffee & Cake
Clinics

The Team

Living Well Hub

Young Adult Events

Ongoing support & co-ordination



Lead professionals

What is getting in the way of this individual's wellbeing?

Do you have all the information you need to help this individual?

What can you do now to help this individual?

What can PPWH do to help this individual?

What additional help, if any, may be needed by others?

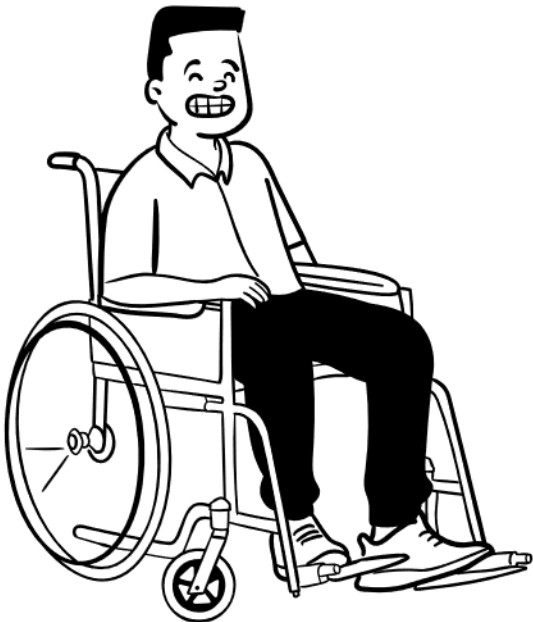


Respite

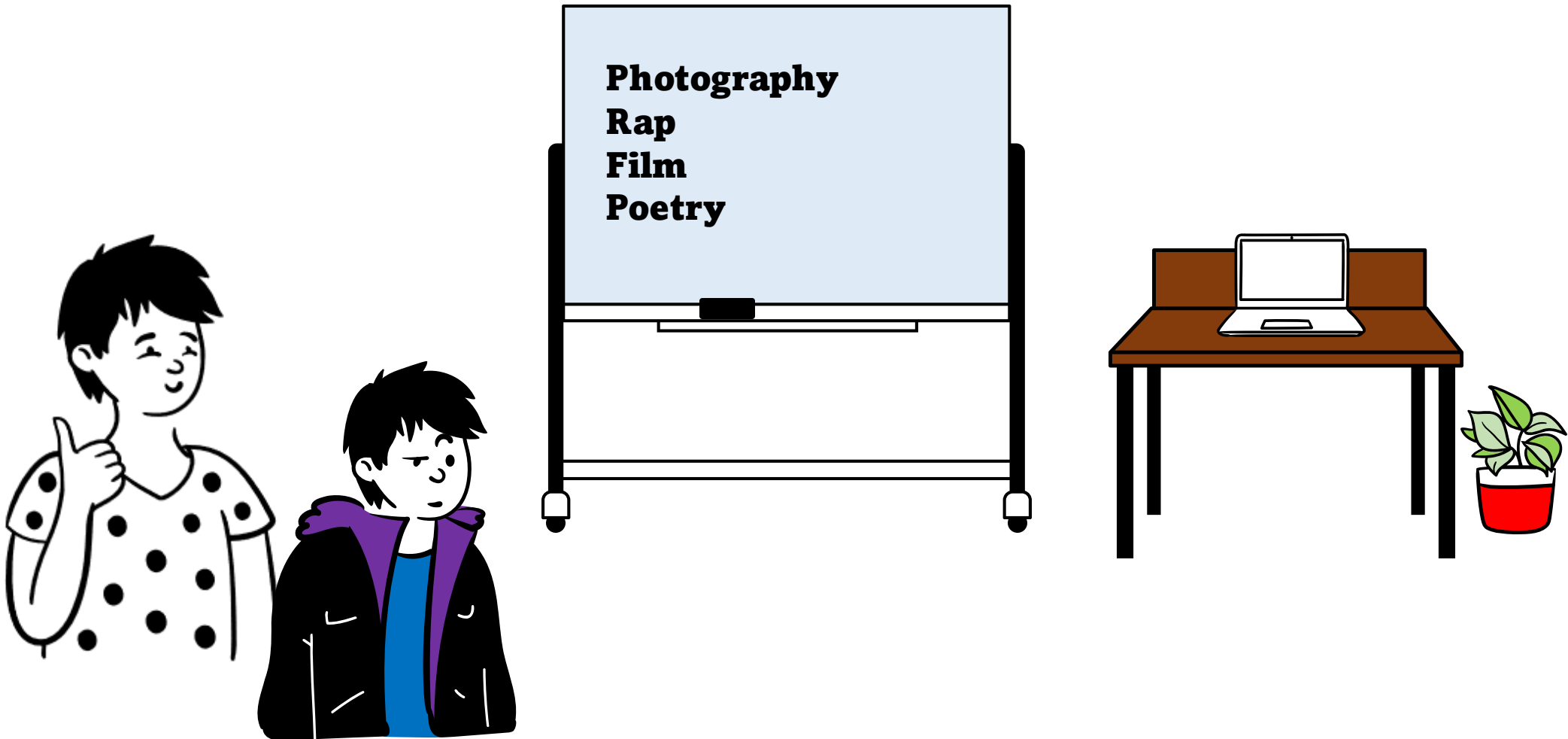
“I went for a break a long time ago... maybe a couple of times a year... if there was a bed. They’d put me to bed too early... there wouldn’t be enough staff, or they wouldn’t know what they were doing with my machines... I didn’t do much, just stay in my room or go shopping... there wasn’t many young people about... But don’t get me wrong... sometimes it was great! We’d go to the cinema and museums, watch football... It was real break for my parents...

I had to stop going though... I was anxious about how they cared for me and it wasn’t like it was for me... at my age...

I want to come to you cause it’s close – to my parents and the hospital... I’ve built up trust with you. I want to make sure you can meet my needs though – that ok? I’m worried about you doing my care, moving me and settling me at night... And you need to make sure that the equipment’s right... I have lots of equipment... at home it’s set up perfect – there’s no point if the equipment doesn’t work...”



Every day is a learning day



Success





“I want to understand the world from your point of view. I want to know what you know in the way you know it. I want to understand the meaning of your experience, to walk in your shoes, to feel things as you feel them, to explain things as you explain them. Will you become my teacher and help me to understand?”

Spradley 1979

Whose role it is?

Let Young People Flourish

https://youtu.be/HY-hLjgzZlg?si=f6V8HfWm_6s-nrMP

Young Adults Short Break Stays

<https://youtu.be/HeD6dimQpil?si=xyKj2pNORQ-BZwtz>

For further information, please get in touch with

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