



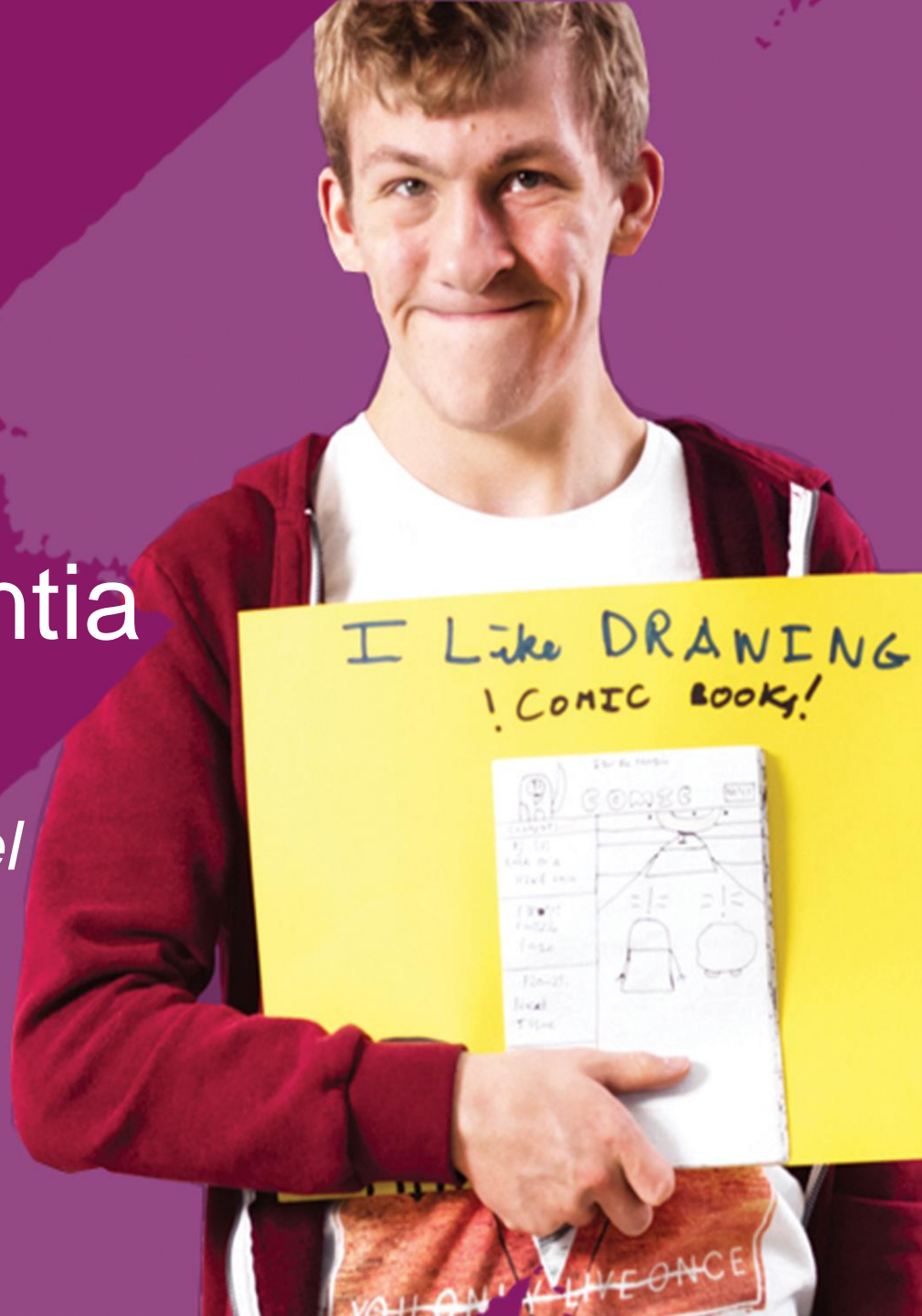
MacIntyre

Providing support...your way

The Emotional Impact of Dementia

Presented by:

Nicola Payne and Rachel Silver



About MacIntyre

We provide learning, support and care for more than **1,500 children, young people and adults** who have a **learning disability and/or autism**, at more than **150 services** across England and Wales



Learning Disability and Dementia

Some facts about Learning Disability and Dementia:

- Figures from one study (Prasher 1995) suggest that more than half of those living with a learning disability will develop dementia once they pass the age of 60.



Learning Disability and Dementia

- People with Downs Syndrome are more likely to have young-onset dementia as they are more at risk of developing dementia from their mid-30's onwards



What we will talk about today



- Brief introduction to MacIntyre
- Rachel and Alison's story
- Reflect on the challenges faced by both Rachel and Alison

Being given a diagnosis of dementia

Since the diagnosis, staff have said they notice the following things and how it can impact a person and their friendships

Struggles to
communicate –
'disappearing
friendships'

People feel
afraid to spend
time with you

Not invited to
social events

Feel isolated
from what you
once knew

Feel lonely
and not
included

Talked about
and talked
over

Relationships can change



“Yesterday I was living without dementia, and now it feels like my whole life has changed over night”

The MacIntyre Way

What we do:

- Upskill staff, friends and family with what is happening to their loved one
- Support friendships and provide the time and care for friendships to continue to blossom
- Allow privacy and time for friends to spend together

People we support:

- Assessment/referral
- Information sharing with person and their family
- Continued Care and Support e.g. Easy Read
- Receive support along the Dementia Pathway
- Developing a support plan agreed by everyone especially the person supported
- Placement monitoring and review

Meet Alison and Rachel



- Rachel and Alison have been friends for over 20 years
- Living together as house mates
- Working together and spending free time together
- Doing what best friends do

Personal Impact of Dementia - Alison and Rachel's Story



A brief snippet of Alison's life



- Alison was a lady living with Down's Syndrome
- She was in her mid 40s when she received a diagnosis of **Alzheimer's disease**
- Her life had dramatic changes which happen very fast
- This is where Rachel started to see **significant changes** within her friend and their relationship

A day in the life of Alison and Rachel

A “*typical*” day for Rachel and Alison would have involved:

- Having breakfast **together** in the flat they shared
- Walking to work **together**
- Spending a working day **side by side** in a café and bakery
- Going home to catch up on the soaps/ listening to music **together**
- Cooking dinner/ house jobs **together**, taking it in turns and routines

The Impact of Dementia – “The Initial Stages”

After Alison's diagnosis:

- Rachel was seen more on her own
- Alison still attended work but her days become shorter and less active (a different pace)
- Rachel needed time to off load her thoughts and emotions – as did Alison
- Alison need more care and attention – as did Rachel
- Things had dramatically changed for the ladies

The Importance of Advocating

Staff helped to ensure that the ladies **spent quality time with each other** so Rachel continued to feel important in Alison's life.

This was also **important to Alison** that they continued to spend that **quality time together**.



What stayed the same in times of change?

- Nothing could take away the bond Rachel and Alison had.
- Alison's needs changed but **their friendship remained as strong as ever.**
- We had to be mindful and creative in how we continue to support their friendship and not let it get lost.

The Role of Staff

- Making sure Rachel was aware of what was happening in Alison's life and how her dementia was affecting Alison's activities of daily living – **in a way that made sense to Rachel**
- Making sure the **rest of the flatmates** had an understanding of what was happening and how things were constantly changing
- Having **honest conversations**
- **Upskilling staff** to have an understanding of what will happen and how progressive this journey may become e.g. End of Life Care

Alison's Progressive Dementia

- Alison began spending more time at home in her flat
- Adapting Alison's environment was necessary (bedroom changes)
- Work came to an end due to Alison's health
- All of this had a massive impact on Rachel, Alison and their friendship

The final days and hours

“If she goes, I go!!”



- The importance of staying at home
- Rachel had a fear of the ambulances/ hospitals but developed an understanding of how important this
- Alison had to be moved to a hospital for specialist care and support in her final days and hours
- Rachel was with her as much as possible in this time

Rachel's continued commitment to Alison



- Rachel will talk to people around her about Alison's health and **share their story**, which she will tell with passion and confidence.
- Rachel feels the need to share this on behalf of Alison and continues to do so



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Thank you for Listening to our story

For more information please get in touch.

T: 01908 230100

E: health.team@macintyrecharity.org

www.macintyrecharity.org

