‘I’LL BE AS ABLE AS I CAN
FOR AS LONG AS POSSIBLE’

‘NICE MAYHEM’ VISITS FROM MY
GRANDCHILDREN – TO SEE THEM
DEVELOP AND SEE WHAT THEY
BECOME.

‘CLARK’

IMPORTANCE OF
SOCIAL SUPPORT

‘MY MIND HAS
KEPT ME GOING’

EMPLOYERS SUPPORT
MADE A REAL DIFFERENCE

‘HAVING A RARE CONDITION
MEANS YOU NEVER HAVE
ENOUGH ANSWERS’
Learning about medication

Accessing local palliative support services

Spending time with grandchildren

Worried about future fear of unknown

Knowing and having people to talk to

Anticipation around loss of independence

“I was reluctant at first about palliative care services given the ‘nature’ of the centre, but my perspective changed after going to the centre.”
"IT STILL HASN'T SUNK IN"

LOSS - NOT BEING ABLE TO TRAVEL OR GO TO FOOTBALL WITH FRIENDS

"HARVIE"

THE OUTLOOK ON LIFE - NOT TO WORRY

GETTING OUT AND MEETING PEOPLE

'AWARENESS OF HOW CURRENT POLITICAL SITUATION IMPACTS HIS CARE

'I DO AS MUCH AS I CAN'
'LIMEFLOWER'

Adopting a new routine

Less able to do things than before

Complimentary therapy

Moodset of moving forward

Long waiting period after diagnosis - lack of information

Social opportunities at the centre

Forward planning, but cautious to not do too much

‘You need someone to prepare you to take it easy’
Trust, openness and honesty in services + staff is really important

Dialogue, planning + involvement in care is important

Specialisation, independence; fun, family time

Inclusive + accessible educational institutions for Rose

Having all voices heard, inclusivity

Life-long learning (for both)
Loss of career (for mother)
But new roles = identity (spokesperson/advocate for palliative care)

Familiarity with care provider is important
The mind is the best key we all have.

Honesty - knowing the truth about what will happen.

Trying to plan each stage but living in the here and now.

Sudden loss of future, lack of control.

Being involved in the ‘hard’ decisions - talking to health professionals.

Important to have a living will.

Writing a blog allowed me to have a huge amount of interaction with people.

‘The Writer’
“Every day is a bonus”

Uncertainty / Unknown Ground Following Diagnosis

Found it hard to open up with family

The Hat Man

Walking daughter down the aisle

Eating healthy, learning to cook

Connecting with church, reading Bible

Continuity in health professional interactions
FUTURE TRANSITIONS IN PALLIATIVE CARE

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