

A borrowed Voice breaking barriers for Cancer Care
Two People – One Voice
2025





Paul Born In 1967 – 3 half years between us – I am youngest of 7.

Paul went to residential School at 8 years fulltime with short visits home. Never learned to read, write, use sign Language or how to communicate with others. Few words he had he stopped saying..



Age 16yrs transitioned to Adult
Psychiatric Care
No Pictures or No Contact until
1990, When I discovered where he
was as Our Lady's Hospital closed
in 1990



- Paul started on medication at 8 years.
- At age 17yrs he had burst appendix.
- Only way it was noticed, when passing poison in his stool.
- Back then People like Paul were deemed challenging, not physically sick or in immense pain bending forward
- He lived in congregated setting, for 37 years, on High dose of, as the only intervention for him medications.

2001 I started advocating for Pauls
medical needs and care – as he was
very sick

Ulceration from throat through to his
gut

Skin grafts on his ears

Weight Loss

- From 2007 he started coming to my home –
first place he stayed beyond an institution in
30ty years and over next 6 years spent up to 5
days with me a week
- In 2013 he got the outcome after a tribunal,
to move and live near me after 37yrs in
Congregated setting at the age of 45 years



First Christmas – Life
beyond Congregated
setting – First family
event – his 50th Birthday



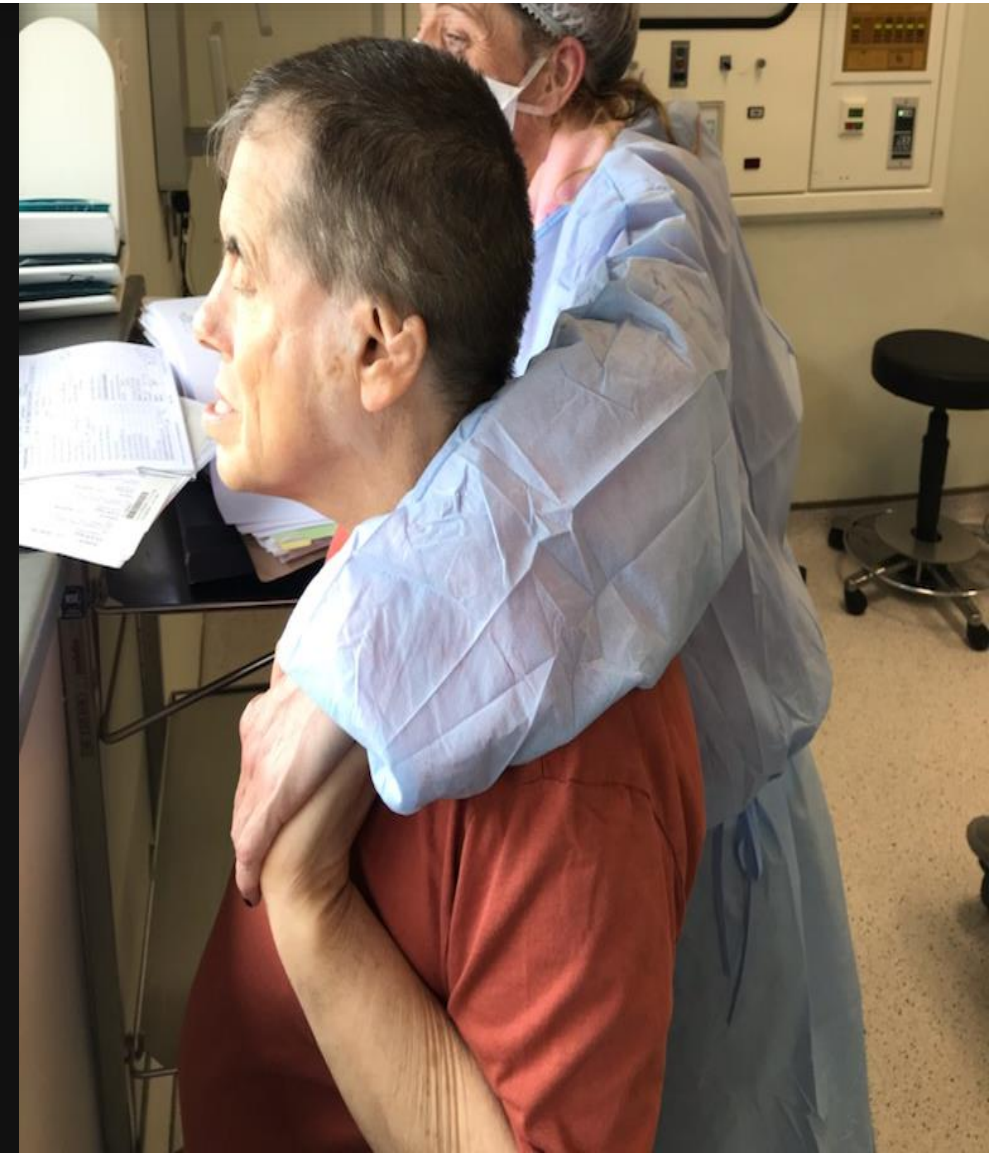
Paul – Diagnosis aged
54years - 2022 of Cancer -
Non-Verbal – Autistic –
Intellectual Disability



*Saying to GP – Something was different this time – as I
have seen Paul up/down weight – on /off medication but
this was different – Feb 2022*

INTUITION




When you don't know
how you know...
but you know you know
and you know you knew
and that's all you need to
know... ”




Operation 10th August 2022

- After 8 months from January to August 2022
- Collapse Jan 2022
- Hemoglobin 6.8 – 3 units and Iron Fusion – up to 9 – on Iron supplement
- March Bloods dropping – Blood in Stool
- Assessments Psychiatrist – Capacity
- High Court – Colonoscopy to be sanctioned
- May 2022 – Colonoscopy and scans if spread – Confirmed Tumor/Cancer
- Met Surgeon – Anesthetic said never operated on Someone like Paul – wasn't going to start – Asked WHY WOULD I PUT HIM THROUGH IT
- 2 Psychiatric reports – Surgeon Report – Another Anesthetist report
- High Court 28th July – if it didn't go to hearing – No operation but it did so sanctioned operation
- Do's Don'ts – what P could tolerate – End of Life Planning
- Only once to theatre – any complications straight to palliative care
- 10th August – Operation – couldn't sign any consent form, on day operation was requested





Pictures 50ty
years apart but
what a journey we
have travelled
together



- As Paul sister it has been my honor
- As Paul's Sister it has been a tough road – as I took the slack
- Would do it all again
- Paul and I are deemed Imperfect to a system that doesn't work because we spoke out
- Yet together we have been Perfect to travel 50ty Years and all Paul has achieved
- So, listen to families and People Like Paul – As there are going to be far more like him as the Paul's of the world stay in the community and want more for their life
- All we ask is listen, as the Paul's of this world only want the same care any other man in his shoes without a disability would want
- My brother was not a case number/ policy /procedure as his sister – He is my flesh/ blood, and he isn't heavy – Just unique – No different to anyone else in this room – All unique in our own way
- He deserved a voice to be heard for his Human rights – as we all do.
- Not complicated – Just real-Life experience for a man who was already Vulnerable
- Thank You – marcella 2025

