

We are Invisible but not Dead Yet

Our renal story needs telling

Dr Debbie Wilson



Study Purpose

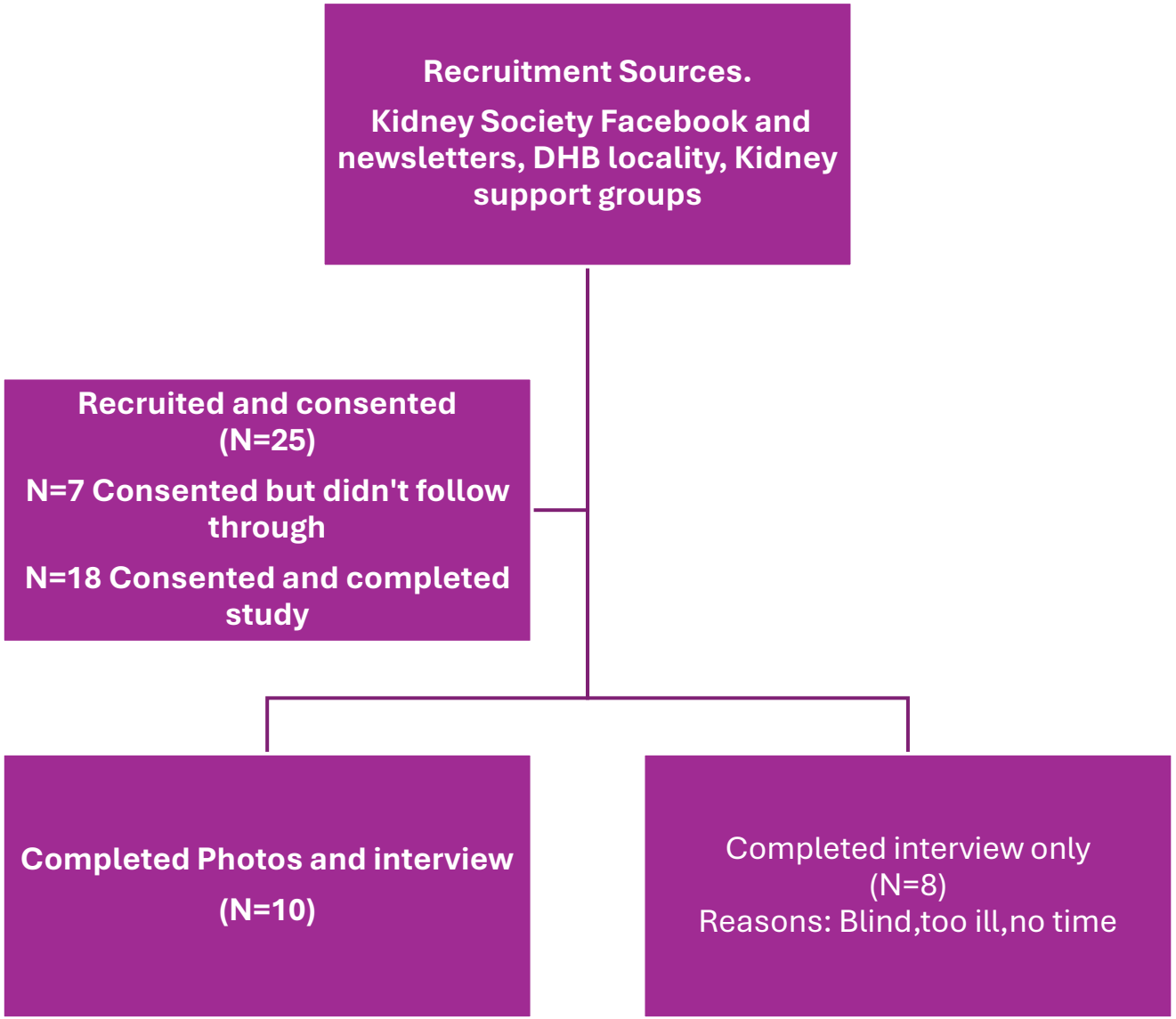
- To explore the lived experience of individuals managing kidney failure through dialysis or transplant.
- To identify factors that could be addressed to help support the mental health and wellbeing as individuals move along the kidney failure continuum.



What is Photovoice?

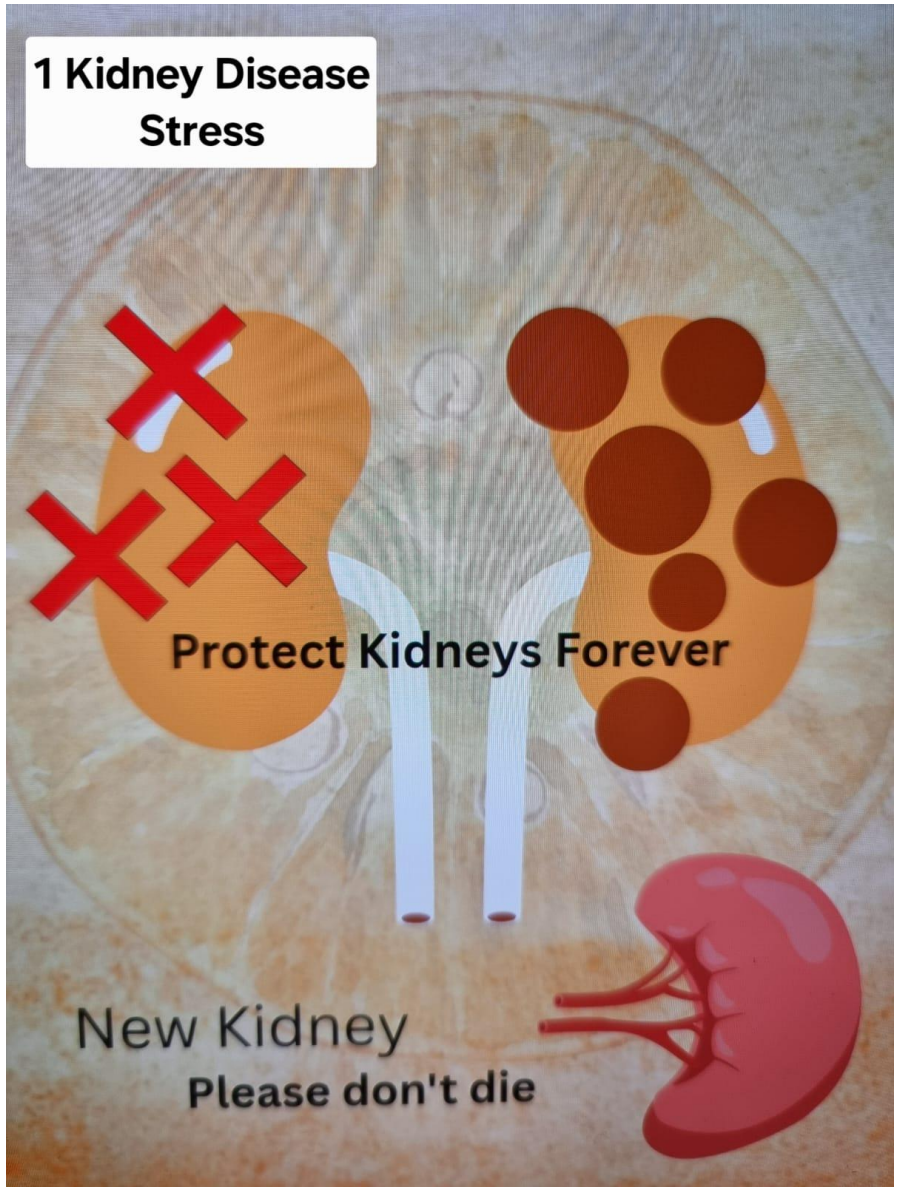
- Photovoice is a participatory visual qualitative research method
- Participants capture photos of their lived experience
- Co-create a story board of their experience and health related issues
- Empowers individuals to tell their story, engage with policymakers, public health services
- Bring attention to the realities of kidney failure in Aotearoa

Recruitment Process



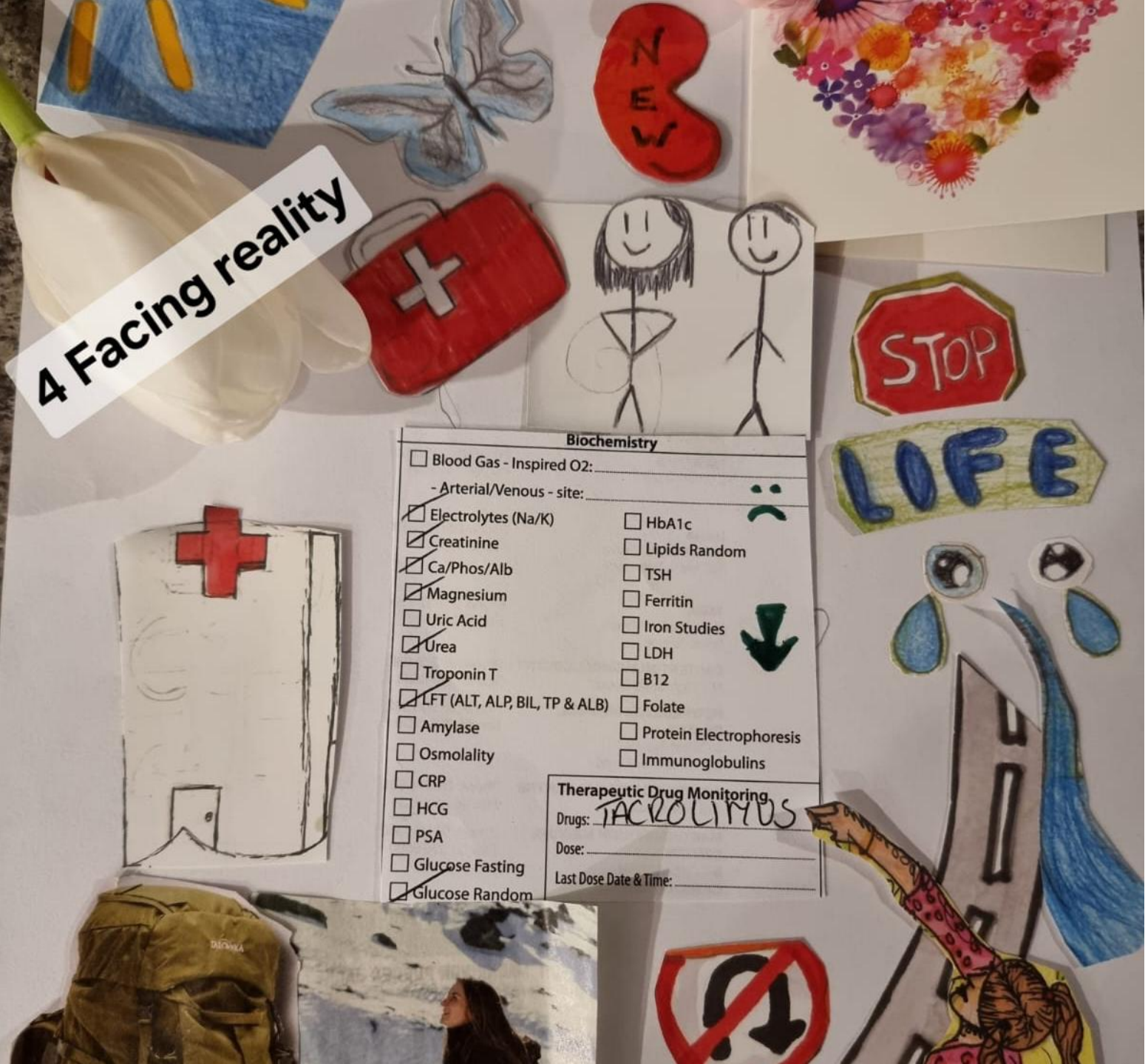
Baseline Characteristic	N=18	%
Mean Age	51	
Gender		
Female	12	67
Male	6	33
Ethnicity		
Asian	1	05
Māori	3	17
Pacific Peoples	7	39
White/Pakeha	7	39
Type of Dialysis		
Hemodialysis	8	44
Home Hemodialysis	2	11
Peritoneal	2	11
Transplant	6	33

Demographics

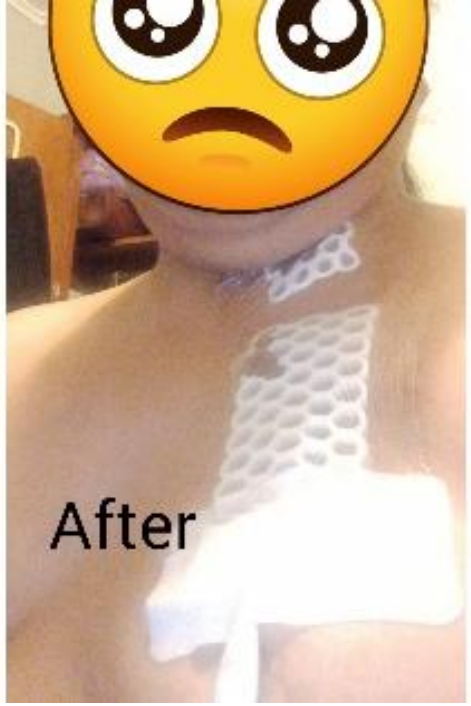

1 Kidney Disease
Stress
Protect Kidneys Forever
New Kidney
Please don't die

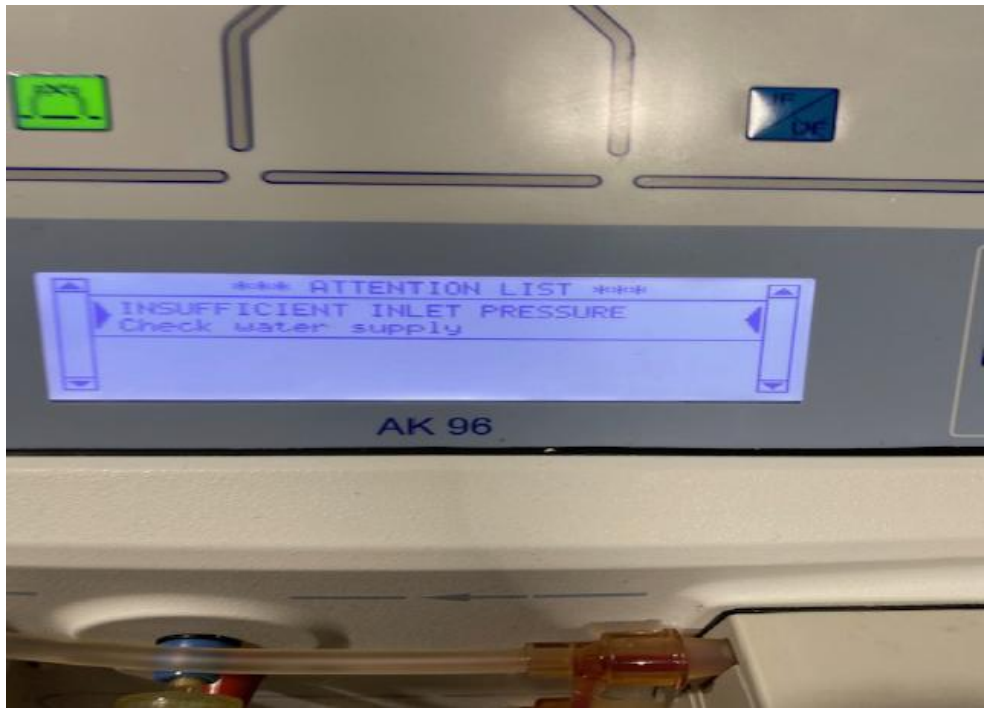
Main Stress



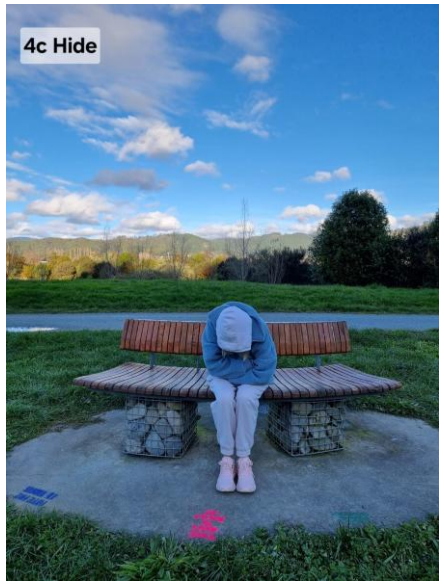

4 Facing reality
NEW
STOP
LIFE
Biochemistry
Blood Gas - Inspired O2:
- Arterial/Venous - site:
Electrolytes (Na/K)
Creatinine
Ca/Phos/Alb
Magnesium
Uric Acid
Urea
Troponin T
LFT (ALT, ALP, BIL, TP & ALB)
Amylase
Osmolality
CRP
HCG
PSA
Glucose Fasting
Glucose Random
HbA1c
Lipids Random
TSH
Ferritin
Iron Studies
LDH
B12
Folate
Protein Electrophoresis
Immunoglobulins
Therapeutic Drug Monitoring
Drugs: TACROLIMUS
Dose:
Last Dose Date & Time:

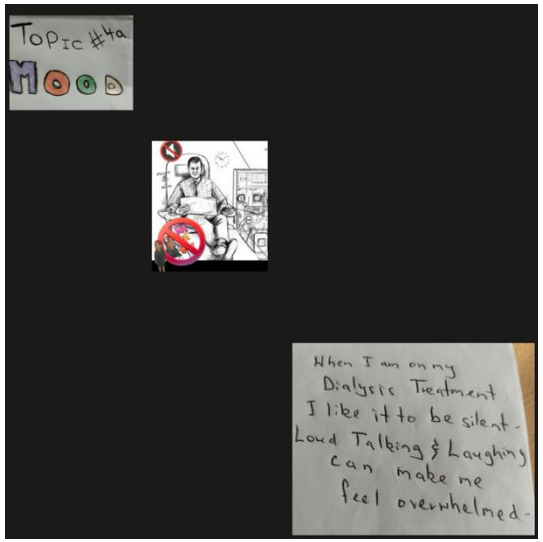

Before


After


ATTENTION LIST
INSUFFICIENT INLET PRESSURE
Check water supply
AK 96

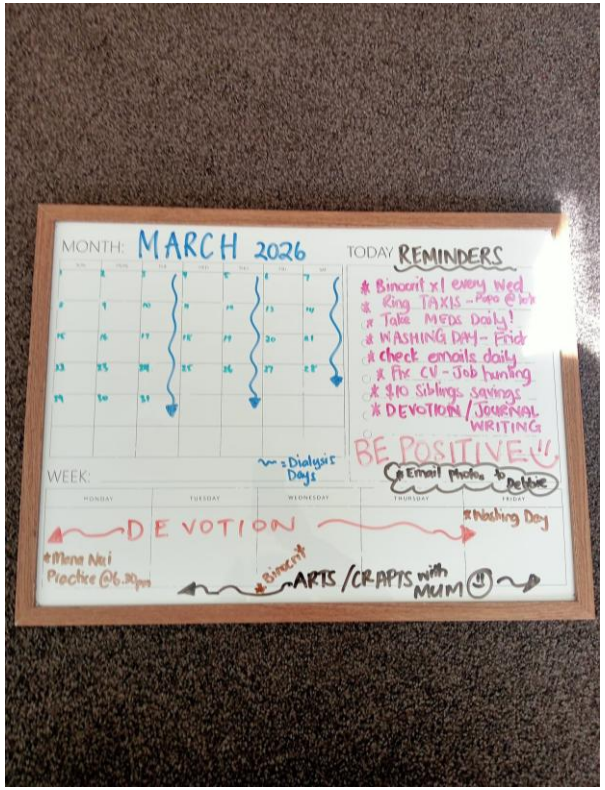


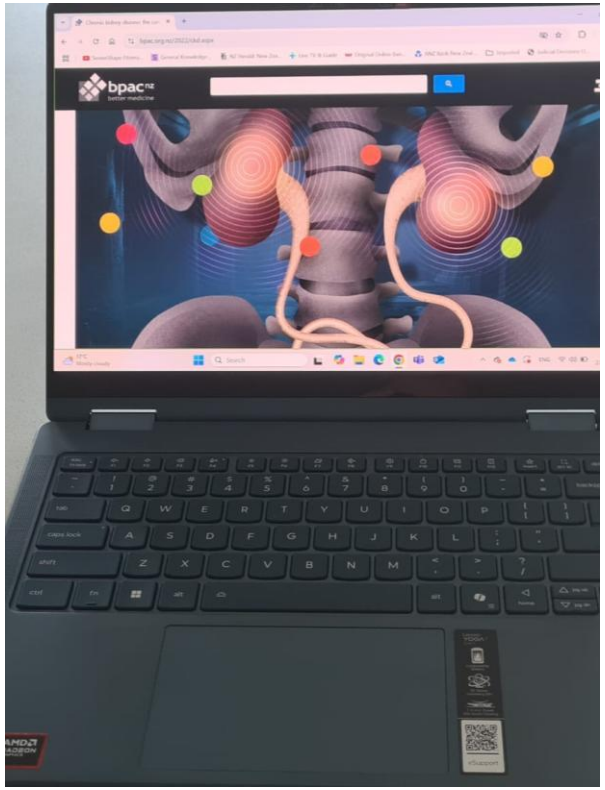




Need to shut shop withdraw







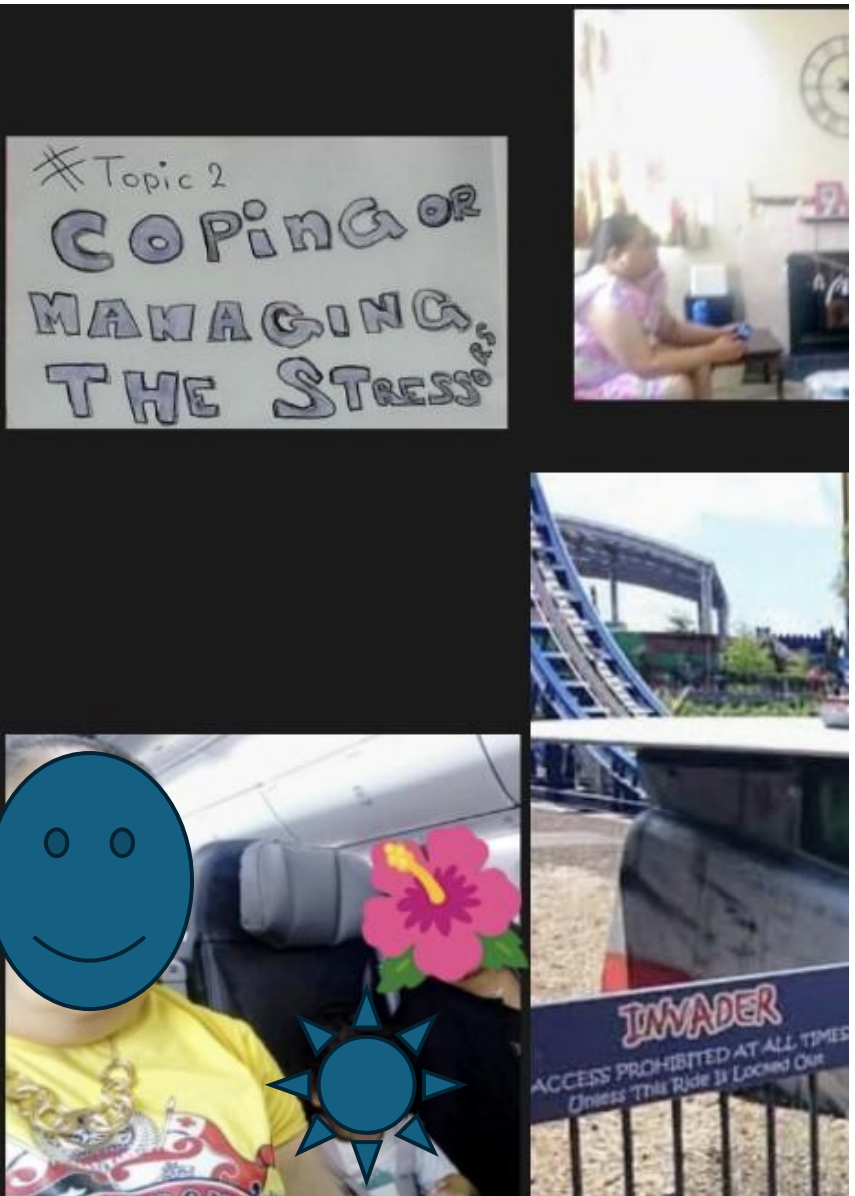


Take Control

PLAN

“Helps build confidence”

Meet others like me







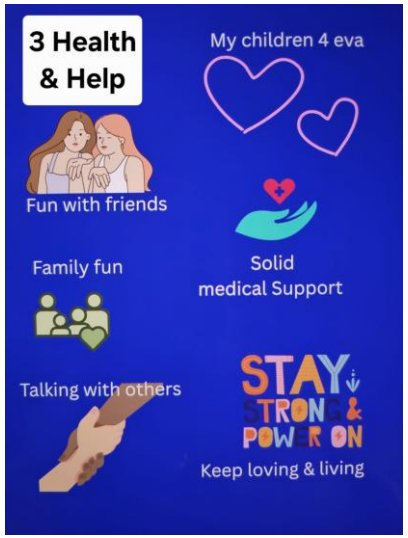
Take the Small Wins







Scaffolding a New Me

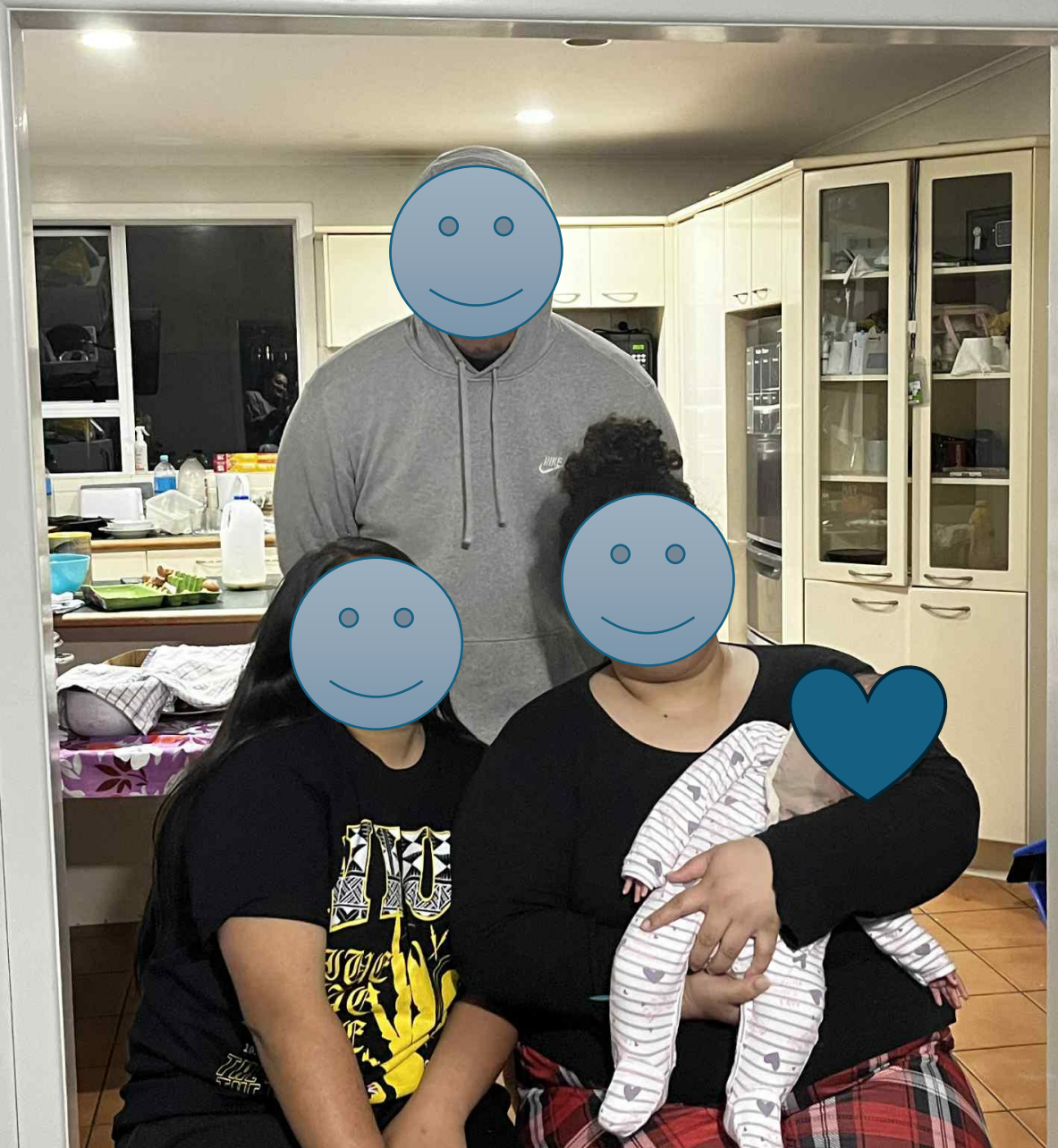






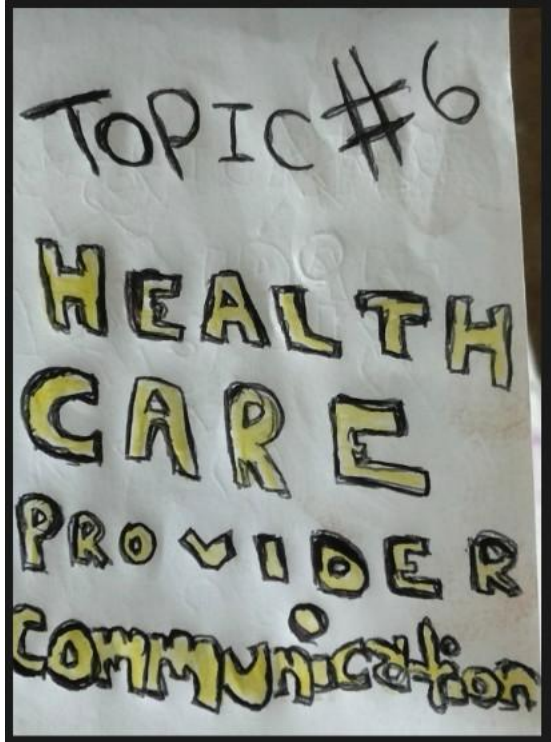


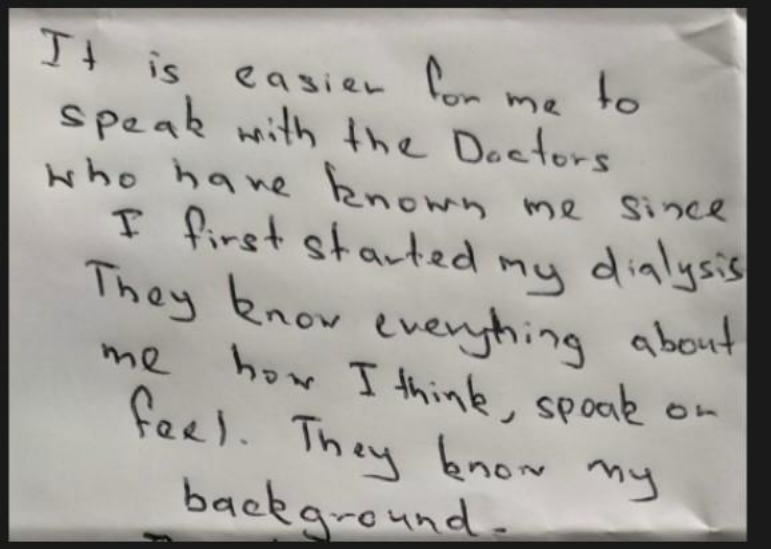
Solid Support

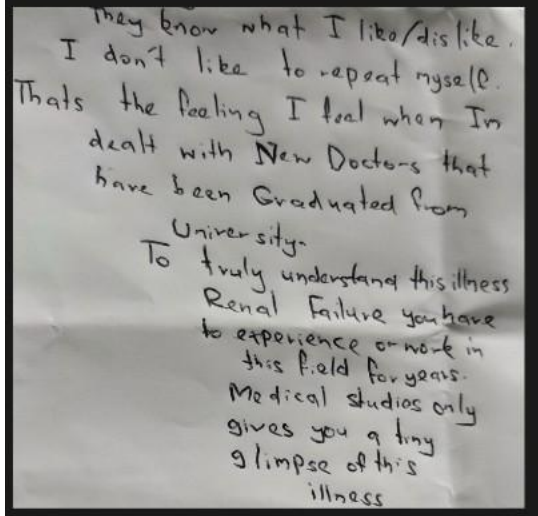


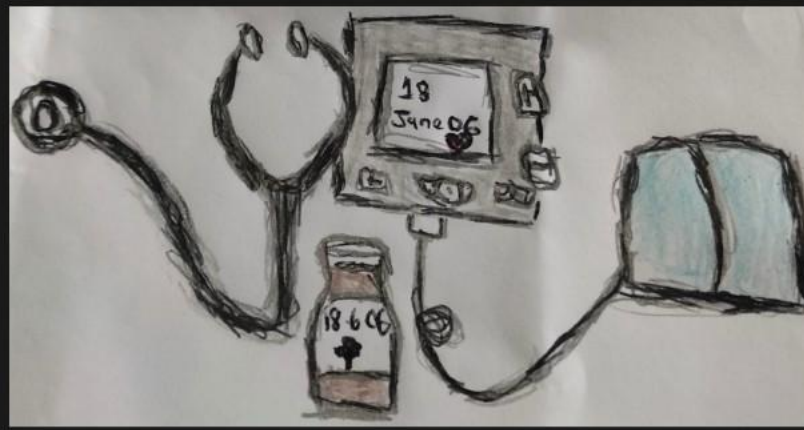



Reachable medical advice & Support
6 Two way communication
Health Support
Doctor Care
ME
Renal Team
GP
PATIENT CARE
Safety Net in place for my health & welfare.
Communicate


TOPIC #6
HEALTH CARE PROVIDER COMMUNICATION


It is easier for me to speak with the Doctors who have known me since I first started my dialysis They know everything about me how I think, speak or feel. They know my background.


They know what I like/dislike. I don't like to repeat myself. Thats the feeling I feel when Im dealt with New Doctors that have been Graduated from University.
To truly understand this illness Renal Failure you have to experience or work in this field for years. Medical studies only gives you a tiny glimpse of this illness


18 JuneOG
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10 Keep Living








Thank you


Last words
Kidney disease needs attention in NZ.
Voices need to be heard.
Lives are being ruined.
People are dying.
Thank you for doing this research
to give a voice to kidney patients
& to help this silent deadly disease be heard.
Thank you