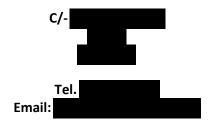
#### **GANG OF FOUR**



1 June 2021

Health and Environment Committee
Parliament House
George Street
BRISBANE
QLD 4000

Email: hec@parliament.qld.gov.au

Re: QLD Voluntary Assisted Dying 2021 – Draft Legislation

We refer to recent communications sent by us to all Qld Politicians as follows:

Dear Member of Qld Parliament

We are four Queensland women known as the "Gang of Four". The inspiration of the group name comes from a book "Gang of Four" (Liz Byrski) about four women (friends) who each shared unique journeys through their mid-lives, supporting each other through the good and the bad times.

As we write this email to you, three of us are in "the worst times" of our lives. All three of us are living with a terminal illness. Three of us are receiving treatment to "buy more time". None of us are well but two of the group are incredibly ill and currently housebound. The fourth member of our group is a retired Palliative Care Nurse Specialist with Post Graduate qualifications in Advanced Palliative Care whose experience includes working within the Calvary Palliative Care group in Sydney. We all came to know each other through our advocacy for Voluntary Assisted Dying Legislation for Queenslanders before two of the group were diagnosed themselves with a terminal illness.

We endorse and embrace the draft Qld Voluntary Assisted Dying Bill 2021 released by the Qld Law Reform Commission. We believe it has been well considered and clearly demonstrates that many voices and opinions have been taken into consideration. It also takes into consideration the legislation of other states who have already passed Voluntary Assisted Dying laws.

We ask you, respectfully, to listen to our voices because we are actually the ones living the nightmare. We are the ones that would seek to use Voluntary Assisted Dying as an end-of-life option. Our Palliative Care Specialist colleague has many years of experience, fully supports exceptional palliative care but acknowledges – based on many years of experience working within the field of palliative care – that no amount of palliative care can alleviate a great deal of suffering that is involved with living with a life-limiting disease.

As real people living through our real-life experiences, we are distressed and dismayed at those who seek to offer an opinion that contrasts dramatically from our every-day experiences of living with a life-limiting disease and all that it brings. We urge you all to actually take the time to listen to the most important voices of all – ours - and the voices of those families who will forever remain traumatised by the suffering of their loved ones (us included).

All of our group have those first-hand experiences of nursing our loved ones and that's why we would prefer not to have to follow in their footsteps.

We acknowledge that in September you will, using your own conscience vote, make a decision that won't actually really affect "many" people personally, but it will have a huge impact on those who have to live their suffering and live and die because of an incurable/terminal illness. This is about an individual's personal choice. For those who seek to oppose, on their own grounds, they would never be forced to take that decision, but to have an absence of compassionate end of life choices, for the rest of us, is nothing short of cruel.

We attach our brief story with you and would appreciate a response from each of you. We welcome the opportunity to talk to you, though two of the group are very, very unwell at this time.

Kind regards

**GANG OF FOUR** 

Therese McLean Tanya Battel Lyn Bailey Beverley Young

#### Further comments re: Draft Legislation

Of **key** importance to us are the following:

#### 12 months' life expectancy

We know from our own experiences of caring/nursing loved ones through harrowing and cruel diseases that suffering can start a long time before the last 6 months (as is contained in the Victorian, Western Australian and Tasmanian Legislation). We concur with the term contained in the Qld draft Bill.

#### **Conscience objection**

We fully respect the right of all *individual* healthcare professionals to have the right of conscience objection based on personal faith, etc. However, **we do not agree** with organisations/entities having that right. The focus needs to be on the individual who would seek to access the legislation. That individual often uses facilities where a particular specialist/specialist team works from. For an individual to find themselves in the situation of suffering and dying, the last thing an individual needs is to have to source new specialists and a new facility at a time when their disease will have already caused tremendous suffering.

#### Telehealth

We understand the Federal legislation that governs telehealth in terms of the link to discussions regarding "suicide". We listened closely to the Tasmanian debate surrounding this issue and understand the initial grounds for introducing this legislation. This must be addressed as a matter of urgency. For those living in remote and regional areas – bearing in mind when you are living with a terminal/incurable disease it can prove challenging to go to a local shop – we could not imagine an individual having to travel

to a central point for the purposes of meeting several specialists at a time when that individual would be struggling to travel. We trust the respective agencies will deal with this matter urgently.

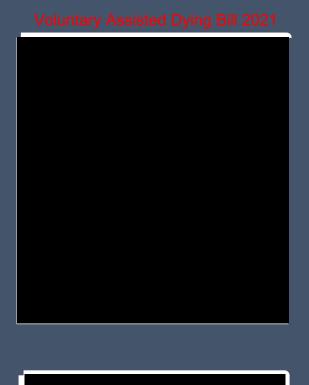
We embrace all aspects of the Qld draft legislation and sincerely trust that Politicians will appreciate the in-depth consideration the Qld Law Reform Commission has given as part of its deliberations. As the Attorney General announced recently, the delays in the release of this draft legislation, was to ensure this legislation fits the "Queensland context". For it to be stripped back and mirror the most conservative model in the world (Victorian legislation), Queenslanders could have had access to this legislation 4 years ago.

We thank you for your time.

Sincerely

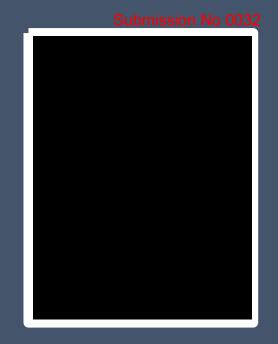
GANG OF FOUR

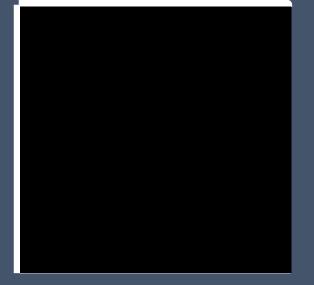
Therese McLean Tanya Battel Lyn Baily Beverley Young



# # GANG OF FOUR







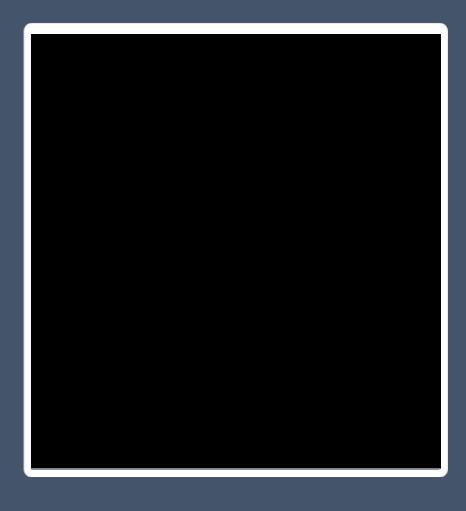
## WHO ARE WE?



Therese McLean
Tanya Battel
Lyn Bailey
Beverley Young

We should let you know we were all supporters of Voluntary Assisted Dying a long time <u>before</u> we found ourselves in a position where three of us would need to have this option for peace of mind

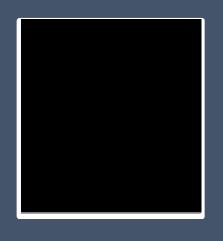
### **Therese McLean**



Diagnosed with metastatic breast cancer in January 2021 –

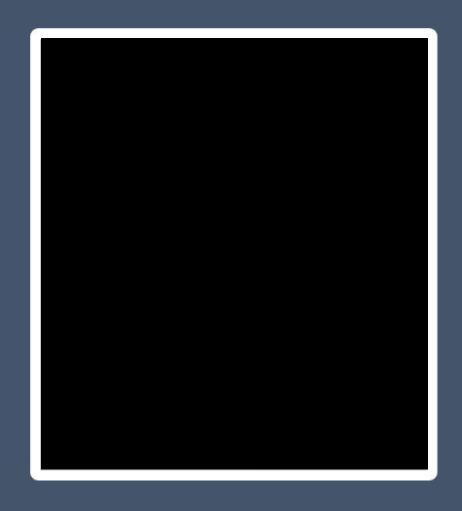
- cancer in both breasts
- metastases to the sternum
- metastases to the lymphatic system

#### Therese's journey so far:



- Double mastectomy operation in January 2021
- Advised that the cancer was extremely aggressive and had spread to her sternum and lymphatic system
- Therese was advised by oncology she was going to need very aggressive chemotherapy for approximately 23 – 25 weeks to be followed by radiation treatment
- Therese commenced the aggressive chemotherapy and was receiving the mega-blast version every 3 weeks, being admitted to hospital as an in-patient for 2 to 3 days immediately after each treatment due to being so ill
- Therese has been so ill after 12 weeks of treatment that the doctors have had to reduce the regime to weekly chemo cycles

Voluntary Assisted Dying Bill 202



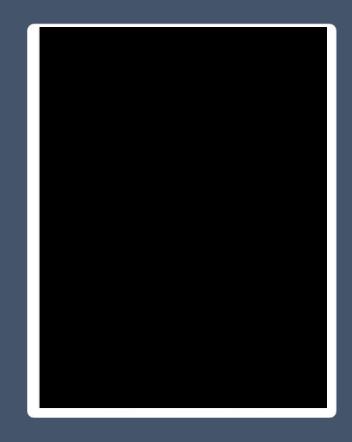
# Lyn Bailey

Diagnosed with Stage IV Vaginal Cancer & Lung Cancer in 2020

#### Lyn's journey so far:



- Lyn presented to her GP for over 12 months re what the GP said was a cyst in the vaginal area
- 12 months later Lyn found herself dealing with a tumour the size of an orange in her vagina and going through the worst imaginable consequences of this before proper medical intervention identified that the cyst was actually a large cancerous tumour in the vagina
- Following further scans, it was identified that quite separately
   Lyn had a cancerous tumour in her lung which had been
   missed during previous follow up scans for her pre-existing
   Chronic Obstructive Pulmonary Disease
- Lyn's treatment has been nothing short of horrific radiation to the lung, 35 sessions of radiation to the vagina and now additional targeted further radiation to the vagina



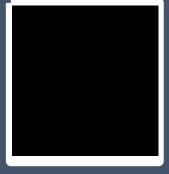
# Tanya Battel Incurable Stage IV Metastatic Breast Cancer

- Diagnosed with Breast cancer in 1997
- Diagnosed with Breast cancer in 2002
- Diagnosed with Metastatic Breast cancer (right lung & pleural cavity) in 2016
- Diagnosed with Metastatic Breast cancer progression (omentum) in 2018

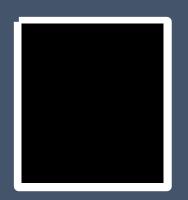


#### Tanya's journey so far:

- Lumpectomy of left breast in 1997 followed by 35 sessions of radiation
- Lumpectomy of right breast in 1999
- Mastectomy of left breast in 2002 following a new diagnosis of cancer
- Mastectomy of right breast in 2006
- Metastatic breast cancer Stage IV 40 mm tumour in right lung and malignancy in pleural cavity - diagnosed in 2016. Commenced continuous chemotherapy and hormonal treatment
- 2018 progression of metastatic breast cancer to omentum –
   chemotherapy treatment changed hormonal treatment changed
- 2020 metastatic breast cancer resistant to chemotherapy
  treatment changed to a new chemotherapy treatment 3<sup>rd</sup> and
  last chemo tablet option cancer markers currently increasing



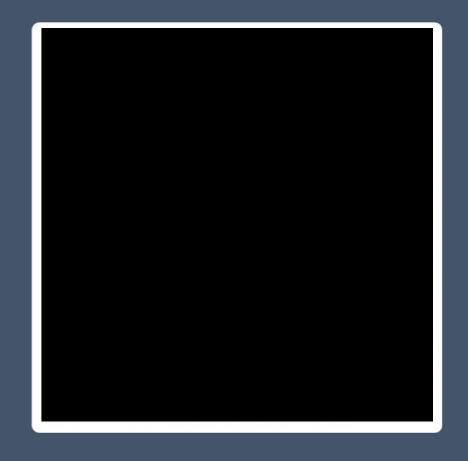
Therese does not know if her current treatment is going to work or not. She is currently house-bound due to the side-effects of her chemotherapy treatment which is ongoing until the end of the year. She is yet to commence radiation treatment.



Lyn is very ill and house-bound. She finds it difficult to even walk. In spite of her treatment she has no idea if there is anything further that can be done to treat the vaginal cancer. She is in a great deal of pain every day.



Tanya was initially told she was looking at "months". She has been taking chemotherapy every day for 5 years and feels unwell most days. Her cancer markers continue to climb and her oncologist has indicated that her treatment is about quality of life given that her disease is not curable.



# **Beverley Young**

# Former Palliative Care Nurse Specialist

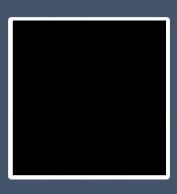
Post Graduate Qualifications in Advanced Palliative Care



#### **BEVERLEY YOUNG – QUALIFICATIONS & EXPERIENCE**

I completed my Nursing Registration with a Diploma of Applied Science (Nursing) in 1988 from the Northern Rivers College of Advanced Education, Lismore, (now Southern Cross University). Following this, in early 1992 I completed my Bachelors Degree in Health Science (Nursing) from Armidale University, while in the Graduate Program at Lismore Base Hospital. In June 1992 I commenced work as a Registered Nurse in Palliative Care at Calvary Hospital Sydney which, at the time, was a dedicated "Hospice" for the dying. Since that time this facility has expanded its services and as at today, comprises a range of other health services.

In 1995 I completed Post Graduate studies in Advanced Palliative Care at The University of Technology Sydney. During my employment at Calvary Hospital, Sydney, a dedicated "Hospice" facility, I attained my accreditation as a Clinical Nurse Specialist in Palliative Care, and was employed there until July 2004. During this time I was seconded to Canterbury Hospital in the capacity of Clinical Nurse Specialist to work alongside Dr. David Gorman, attending Palliative Care Specialist from Calvary Hospital. I served on the Calvary Community Palliative Care Team additionally, as a Consultant. The last four years at Calvary I was a Level 11 Supervisor.



- Beverley supports the delivery of exceptional palliative care but embraces the need for Voluntary Assisted Dying Legislation based on her experience that even the best of palliative care cannot alleviate all end of life suffering
- Bev lodged her submission to the Qld End of Life Choices Inquiry in 2019 stating:

"One would hope that having all the advantages of the latest and most effective treatments it would be possible to control—the worst of any side effect; sadly this is just not so... for a small number of patients, and certain disease processes, the side effects can be so horrendous that the prospect of those experiencing such side effects and trying to 'carry on' is unbearable. I am not being melodramatic, I am simply stating a fact, based on my experience and based on my observations and attempts, as a palliative care nurse specialist, to alleviate those symptoms.



In response to those who oppose Voluntary Assisted Dying Legislation, Beverley has previously stated:

"I only have one comment for all of these people (who oppose): Tell me you have stood at the side of someone dying, watched them suffer intolerable pain – or listened to them drowning in their own body fluid – or heard them desperately trying to take in breath when they are fighting asphyxiation – or vomiting faeces – AND ONLY THEN WILL I LISTEN TO YOUR OBJECTIONS - because I've witnessed all of these things – many times – and stood by while the very best of Palliative Care wasn't able to address any of these things."

We haven't shared with you the absolute nitty gritty of what our treatments bring and their side-effects

We haven't shared with you what it is like to live with an incurable disease and to know that our journeys will get much worse – when we already feel that we have been pushed to the brink

We ask you to appreciate that collectively we have shared enough information with you to give you insight into our real life experiences and you will hear our voices

We are more than happy to provide this detail should our experiences be called into question

This is OUR journey. Voluntary Assisted Dying should be OUR choice





Every day we message each other in our Gang of Four Group to check on each other, support each other, through our respective journeys to hell and back — through days and nights that no-one would understand unless they walked in our shoes





Please listen to OUR voices
We deserve End of Life options
Please vote for Voluntary Assisted Dying
for Queenslanders

