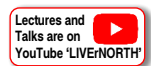




**Newcastle University**  
School of Arts and Culture



Peoples Fundraising 

**Liver** NORTH  
LIVER PATIENT SUPPORT  
run entirely by unpaid volunteers  
supporting liver patients since 1994



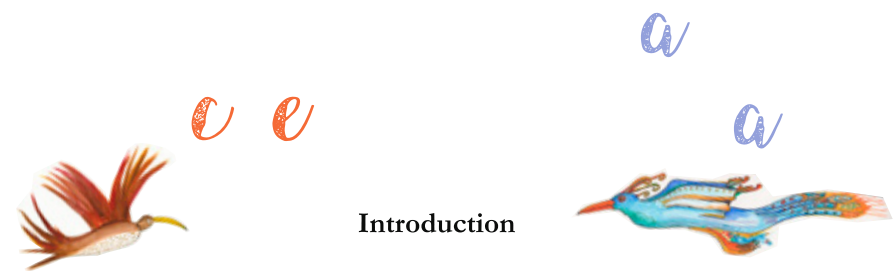


## Acknowledgements

This leaflet was made possible by the commitment and creativity of all participants in the LIVERnORTH creative workshops:

Rachel Beadle, Elizabeth Bennett, Marian Godwin-Clifford, Yvonne Gray, Susan Hall, Michael Hartnack, Siân O'Dea, Ian Plant, Ken & Olivia Weeks. Many thanks to all of you!

Special thanks also to Prof. Derek Manas and his staff, to John & Joan Bedlington and everyone at LIVERnORTH for their foresight and generous support of this innovative project. Finally, thanks to all those living with liver disease, or caring for those who are suffering: you have inspired this work.



Welcome to *Our Livers, Our Lives*, a collection of poetry and art produced by people affected by liver disease, and funded by LIVERnORTH. The work in this leaflet voices first-hand experience of liver disease, treatment, loss, and also celebration. We hope you read and see here things that make you think, make you smile, and help you feel less alone.

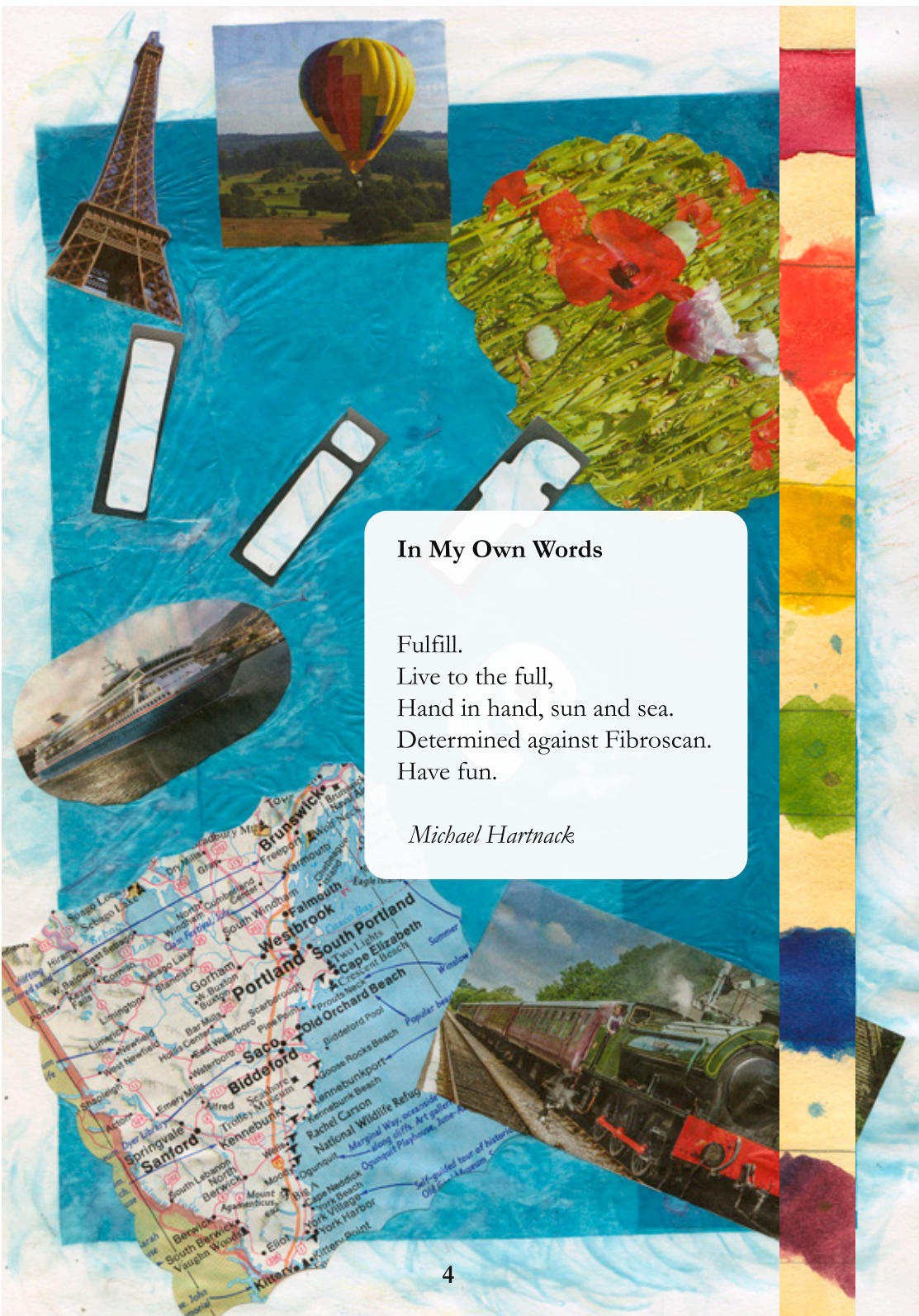
'Poetry should be part of every modern hospital', as much-missed Tyneside poet, Julia Darling said. *Our Livers, Our Lives* continues Julia's quest: to use poetry to break down barriers between doctors and patients; to help patients feel 'in charge again' of their experience; to include poetry in medical leaflets as often as possible.

*Our Livers, Our Lives* is part of the first stage of a research project supported by LIVERnORTH, the Institute of Transplantation, and Newcastle University's Institute for Creative Arts Practice. It has grown from a series of creative workshops at Newcastle's Freeman Hospital, and is now set to expand into more far-reaching education work. As one of the contributors to the leaflet remarked, 'I would really like to see more workshops like this in all departments of the hospital'.

Everyone will come to this leaflet in a different way, with a different perspective. We're glad it has found you! It's here to improve public understanding of the experience of liver disease and treatment. It's here to educate healthcare professionals who care for liver patients. It's here to reassure and talk straight to those who face illness and transplant, or who've recently gone through difficult times. In the voice of another workshop participant, *Our Livers, Our Lives* is here to 'smile and speak in a language we understand'.

**Christy Ducker**  
**Emma Holliday**





### In My Own Words

Fulfill.  
Live to the full,  
Hand in hand, sun and sea.  
Determined against Fibroscan.  
Have fun.

*Michael Hartnack*

### How to Behave with a Liver Patient (after Julia Darling)

Approach us without judgement.  
Remind yourself that, like you, I have a story.  
Please don't assume.  
Speak to me as if you actually care.  
Don't say, 'You could lose a bit more weight'.  
Don't say, 'How are you?' in a disengaged manner.  
And please

Please

Don't say, with disdain, 'You have a typical Geordie liver.'  
But do say, please, 'I love the colour of your dress.'  
Say, 'Is there anything I can do to help?' or  
'How can I make you more comfortable?'  
Remember I'm me, that story, I am  
Vulnerable and I'm scared.

*Yvonne Gray*







### Self-Portrait

I am a tea shop with rattling cups and trays.  
My tea warms you, soothes you,  
scalds you when spilled.  
My chipped cups tell you of a time before today.  
You are invited.

My thoughts are like the steaming kettle, whistle-shrieking,  
the jangling bell  
the tea leaves swept away by the draught.  
My arms in the soapy sink reach for rose-patterned cups slipping  
away, nothing there.

*Marian Godwin-Clifford*

### Let's Celebrate (after Mandy Coe)

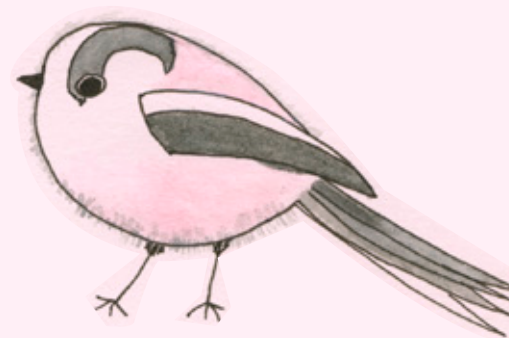


What it is to lie in bed without pain  
and feel the comfort of my pillow,  
to be able to eat whatever I want  
and not have nausea hanging over me,  
to look out the window and see  
a familiar scene, not a view from the ward  
onto patients struggling outdoors.

I celebrate all these things.

What used to be mundane are now  
luxuries to enjoy and be thankful for.

*Susan Hall*





## Why Me?

Lying on the hospital bed  
night after night, thoughts spin in my head –  
it's not my fault this is happening to me  
but still I have to deal with it, how I can see  
the acne, the pains, the crying of a river,  
all brought on by my ever-failing liver.

The wait for a new liver's the hardest part of all,  
on tenterhooks for that all-important call.  
My body lets me down in every single way  
but eventually it's my turn, *today will be the day*.

The feelings I experience are those of joy and fear –  
the doctors are going to fix me, they make it very clear.  
I awaken one week later, in intensive care  
with my family all around me, relief for all to share.

Now four years down the line, my liver's working great.  
I'm fitter and stronger than before, and I'm nearly 38.  
I live a full life every day now, no longer a hospital loner,  
all because of the gift of life from my very special donor.

*Ian Plant*



## Sometimes

*(after Sheenagh Pugh)*

Sometimes the car doesn't crash  
and sometimes the gift is right.

Some years the flowers grow  
and the weeds don't thrive.

Sometimes the shoe doesn't fit.

Sometimes the car passes its MOT first time.  
Sometimes the procedure works first time.

Sometimes there are no side effects.

*Marian Godwin-Clifford*

MY BLOOMING LIVER



## Letters to my Sister Hazel

A letter to say *Thank You* for being my sister and friend and mentor

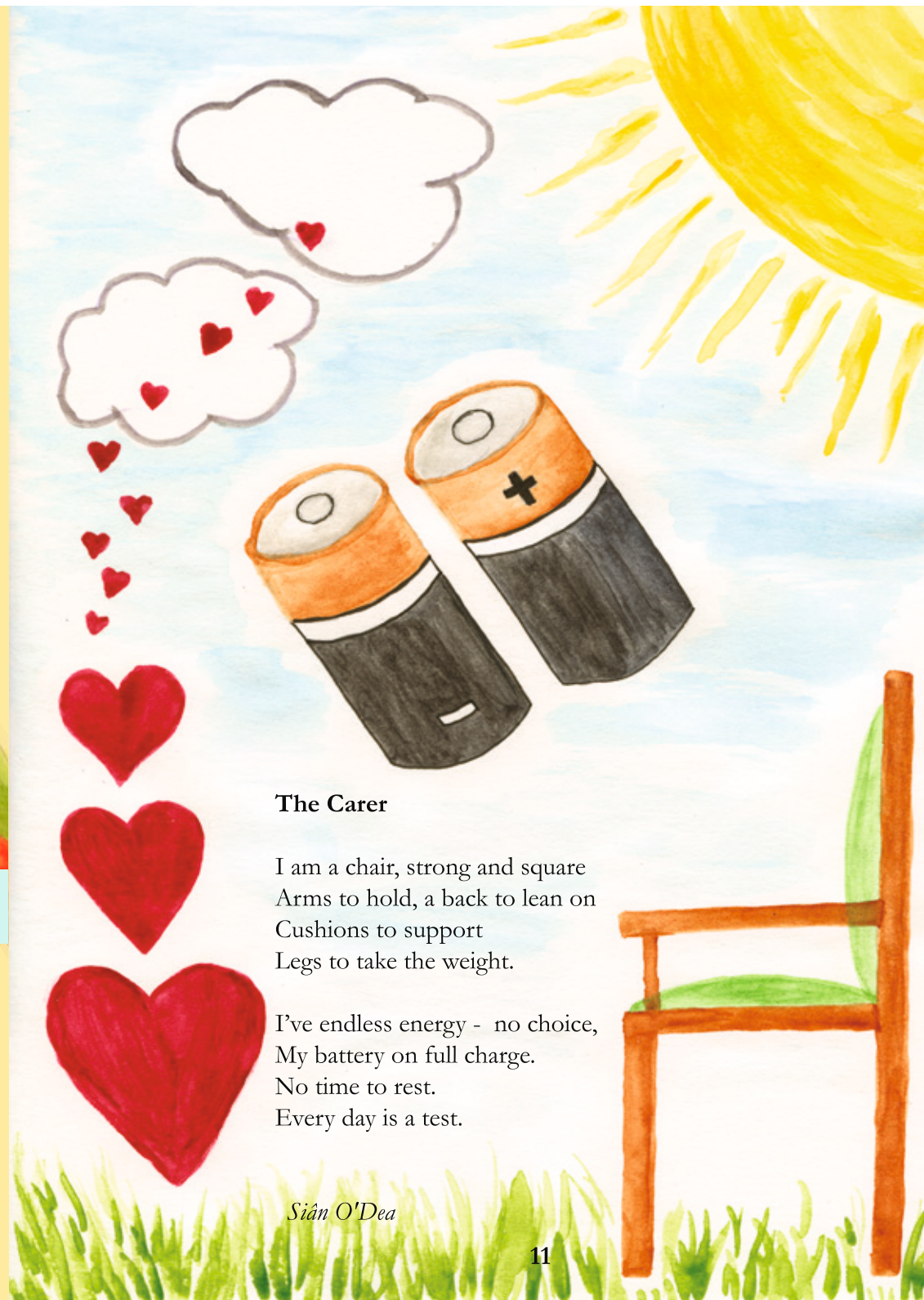
A letter revisiting happy days of memories we shared

A letter to say *you taught me that*, for so many things

A letter saying yesterday, today, tomorrow the world is a sadder place without you

A letter to say, like you, I won't give in to illness

*Elizabeth Bennett*



## The Carer

I am a chair, strong and square  
Arms to hold, a back to lean on  
Cushions to support  
Legs to take the weight.

I've endless energy - no choice,  
My battery on full charge.  
No time to rest.  
Every day is a test.

*Siân O'Dea*



## To Be Honest

I always feel rather heavy,  
like a big, brown, baggy settee  
with little energy to do the things  
I want to do. I want to shine  
brightly like the sun, but  
there's always a mist, drizzle  
hanging over me.

I look in the mirror and what do I see?  
Certainly not me!  
The image is yellow, swollen  
with patchy hair. I've acne  
and smell of toxins. Unclean,  
I'm not the way I want to be.

You can't see my liver but you can  
see my belly – swollen, extended  
with overhanging skin and  
a deep 'Mercedes' scar.

*Susan Hall*



## 'The substance of things hoped for'

Sometimes life writes a story different to the one hoped for.  
Some years pass so quickly but imagined hours don't move at all.  
Sometimes inadequacy overwhelms me but the children thrive,  
Life persists, hopes and dreams adapt but God doesn't fail.  
Sometimes I wonder what, if and why.  
People misunderstand, judge and condemn  
Or offer comfort and hope – they become a new inspiration.  
Sometimes our best intentions falter.  
Sometimes our expectations must change.

May this be our new influence and hope.

*Rachel Beadle*



## In My Own Words

Beach hut  
Sun is shining  
Drink and biscuit in hand  
Battling against cancer chaos  
Keep on  
Keep strong  
Live long  
My one

*Siân O'Dea*



When your husband is in hospital for a long time

-  The warm glow of little things that can bring joy (even on the darkest days).
-  The strength you need to keep carrying on. Dig deep.
-  The pain of bad news to be faced (again and again).
-  The tireless commitment and effort of staff to keep trying even when things seem hopeless. Never give up.
-  For all the precious moments spent together and for sunshine to restore energy.
-  Hope to hold on to. Hope that better hours and days will follow this one.

## Let's Celebrate, Again

Let's celebrate the breakfast table,  
the hiss of steam at the coffee machine,  
the heat of the mug on the cool table top,  
the snoring dog beneath our feet.

Let's celebrate how we washed the dishes  
and nothing broke. The water warm and silky.

These are the moments, the everyday,  
the mundane places where I feel love.

*Marian Godwin-Clifford*







## Walking the Dog Whilst Ill

Oscar  
Loves playing.  
Walk hand in hand,  
Fight against infection, drink wine,  
Enjoy.

*Ken Weeks*

## Please Try This

Approach us with a welcoming smile.  
Try to be interested – we are individuals.  
Be professional.  
Please don't look down on us.  
Be honest.  
Be caring.  
Please say, 'You're doing well.'  
Be friendly, please –  
We are interested in you too.  
Remember we are worried  
Frightened  
And ill

*Olivia Weeks*





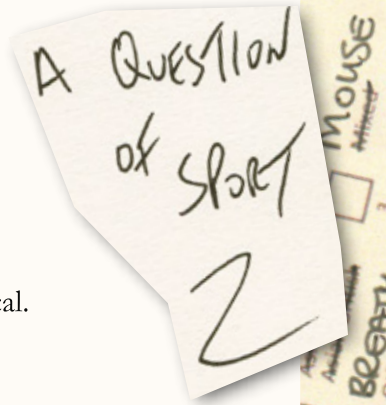
## Do They Know?

Do they know when they look and stare?  
Is it because I'm yellow? Do they really care?  
My belly's large and full of fluid –  
I struggle to walk, and my body's polluted.

No cause of my own – this illness is biological.  
Home for now is the Freeman Hospital –  
I wait and wait for week after week.  
Not a kidney or a heart, it's a liver that I seek –

Finally, after living the hardest of days  
with biopsies, testing and all of the X-rays,  
my prayers have been answered – I might be OK.  
*I'm a lucky man*, I say to myself each day.

*Ian Plant*



## Butterfly Effect

Sometimes the big worries end up no worry at all.  
Some years, the butterflies seem to desert us  
and the next year the rare ones thrive.  
Sometimes the white walls are blank and empty  
but people paint them with butterflies  
and the walls become alive.  
Sometimes our best intentions are mistaken;  
sometimes they are seen as we meant them  
and, like butterflies, land gently.

May you always notice the butterflies.

*Yvonne Gray*





## Our Livers

My Mother had an illness  
Its name is PBC  
Now only those who have it  
Will know just what it means

How that illness treated her –  
She suffered with the itch  
With not an area on her  
Where it didn't hit.

It gradually took over –  
Tired the whole day long  
In those days medicines  
For her: None.

And now I have that illness  
I know just what it means

But things have since moved forward –  
I take Urso and other magic pills.  
For my Mother there were never  
Such helpful daily frills.

My liver isn't normal  
It's just not right,  
It inherited this something  
Which makes it spiteful and tight.

I have to say I'm lucky  
As I rarely have the itch  
Which for my poor Mother  
Was such an ugly bitch.

While the illness takes the front seat,  
I must tag behind –

I'll continue looking onwards  
I will not be defined.  
I won't allow this illness  
To shadow or to blind.

I believe in looking upwards,  
To let the sun keep shining true.  
The illness is just an illness  
And it must be worked through.

I remain ever hopeful  
And like to think I'll see  
A magic pill arrive one day  
To end this PBC.

*Elizabeth Bennett*

## Colours to combat cancer chaos

### Let's Celebrate, Too

The freshness of the air after rain  
The glittering drops on the deep green grass  
The sunshine and shimmering light of a summer evening  
The fragrance of the flowers blossoming  
The gentle breeze blowing across tired skin and eyes  
Brightened by the new found freedom of being home,  
A home now full of colour and promise  
And forgotten corners full of treasure.

*Siân O'Dea*



3 SHADES OF JAUNDICE

3 SHADES OF GOOD HEALTH

### Instructions for Doctors

Approach us as you are –  
We don't want a false reaction.  
Sit down at our level.  
Please don't tower above us.

Smile and speak in a language we understand.  
Treat us with respect and not as a nuisance.  
Don't just leave us with a leaflet telling us  
All the horrors of post-operation.

Can we hug you?  
Can we have a joke?  
Can we ask you about yourself?

Remember – doctors get ill too.

*Susan Hall*

It is lovely to sit surrounded  
by nature when you are feeling  
unwell. It helps to heal.



GREEN IS MY COLOUR.  
SO RESTFUL.  
THE COLOUR OF NATURE



### Lastly, Celebrate

The book I'm reading.

Two sessions of sleep.

Seeing my street quiet and carpeted in rain.

Being settled. Feeding the birds with a peach.

How I never waste time.

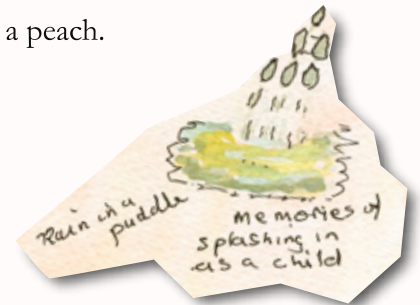
How I cut apples, cook and smell  
the honeyed sweetness.

Let's celebrate my aunt's recipe –  
how I beat the cake,  
bake, ice, and share.

*Elizabeth Bennett*

Good Days

BAD DAYS









## My Own Lines

[illegible]

*Lifesaving Poems*, ed. Anthony Wilson

1. Liver Patient Support
2. Accommodation for patients & families
3. Autoimmune Hepatitis
4. Alcohol and Liver Disease
5. Looking After Your Liver
6. Primary Biliary Cholangitis (PBC)
7. Coping With Stress
8. Primary Liver Cancer
9. You and Your Consultant
10. Primary Sclerosing Cholangitis (PSC)
11. Lifestyle and your Liver (MASLD/NAFLD)
12. Liver Disease
13. Skin Care for Liver Patients
14. Diet and Liver Disease
- 14a. Nutrition in Liver Disease
15. Hepatitis C
16. Travel Insurance for Liver Patients
17. Hepatitis E
18. Fatigue in Liver Patients/A Patient's Journey
19. Scanning - a short guide (*aka Understanding Tests*)
20. Liver Cirrhosis Self Management Toolkit \*
21. Exercise & Osteoporosis in Liver Patients
22. Hepatic Encephalopathy
23. Our Livers, Our Lives
25. Allowances (DLA & PIP)
26. Compensated Liver Cirrhosis
27. Hepatitis B
30. Wellness Walks - several available

\* only from your doctor or healthcare professional

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