



Access
Opening a cage to freedom

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Be with people who help your being



I Know Why The Caged Bird Sings

Maya Angelou

The free bird leaps on the back of the wind
and floats downstream till the current ends
and dips his wings in the orange sun rays
and dares to claim the sky.

But a bird that stalks down his narrow cage
can seldom see through his bars of rage
his wings are clipped and his feet are tied
so he opens his throat to sing.

The caged bird sings with fearful trill
of the things unknown but longed for still
and his tune is heard on the distant hill
for the caged bird sings of freedom

The free bird thinks of another breeze
and the trade winds soft through the sighing trees
and the fat worms waiting on a dawn-bright lawn
and he names the sky his own.

But a caged bird stands on the grave of dreams
his shadow shouts on a nightmare scream
his wings are clipped and his feet are tied
so he opens his throat to sing

The caged bird sings with a fearful trill
of things unknown but longed for still
and his tune is heard on the distant hill
for the caged bird sings of freedom

Kath and Len's story

"Protecting Our Parents"

BBC Documentaries Production,
broadcast on BBC TWO
April / May 2014.

Producer Alice Perman



Kath

- Kath is 87 and has mild dementia – frontal lobe – as well as COPD, severe arthritis and diabetes. She is bed bound and determined to stay in her home come what may.
- She lives with her husband, 89, who has mild dementia as well, and whilst he is mobile he is very frail.
- Kath has phoned 999 over 500 times including 33 times in one day, even though she has carers 10 times a day.

What should Kath's access look like?

How do we meet her needs?

Mandy

- Mandy (35) has anxiety and depression. Her mother had it too. Mandy looked after her before she died of lung cancer.
- Mandy's anxiety is understandable – her son was taken away from her to be fostered by her boyfriend's parents when she couldn't cope in the postnatal period. She is fighting for his return 8 years on.
- She gets hemiplegic migraine, which terrifies her and everyone around her (including her doctors). She has had over 30 CT scans in various A&E departments in 10 years.
- She was taken to A&E/ER 200 times in one year.

What should access look like to Mandy?

What would meet her needs?

Grant

- Grant (52) has recently moved GPs as no-one understands him. He usually gets 'thrown off' lists for being aggressive and argumentative.
- Grant's parents died recently – mum with cancer, dad with diabetes.
- Grant's family think he hears voices – has done for years. But he refuses assessment.
- He has recently developed polyuria and polydipsia
- He refuses blood tests as he doesn't want anyone having samples of his blood. He would want it putting back in him after.
- He gets agitated very easily and cant wait in the waiting room for more than a few minutes – if he does he walks out and misses his appointment.

What should we do to help Grant get healthcare?

How do we make health care make sense to Grant?

Billy

- Billy is homeless. He looks a lot older than he is.
- People walk past him. Most don't even notice him anymore.
- He smells, he shakes, he talks to himself.
- He has no GP. He gets no letters. He has no address.

Who is bothered about Billy getting access?

<http://www.youtube.com/watch?v=tqyACm5OQOM>

**You only have to let the soft animal of your body love
what it loves.**

Tel me about despair, yours, and I will tell you mine...

Whoever you are no matter how lonely,

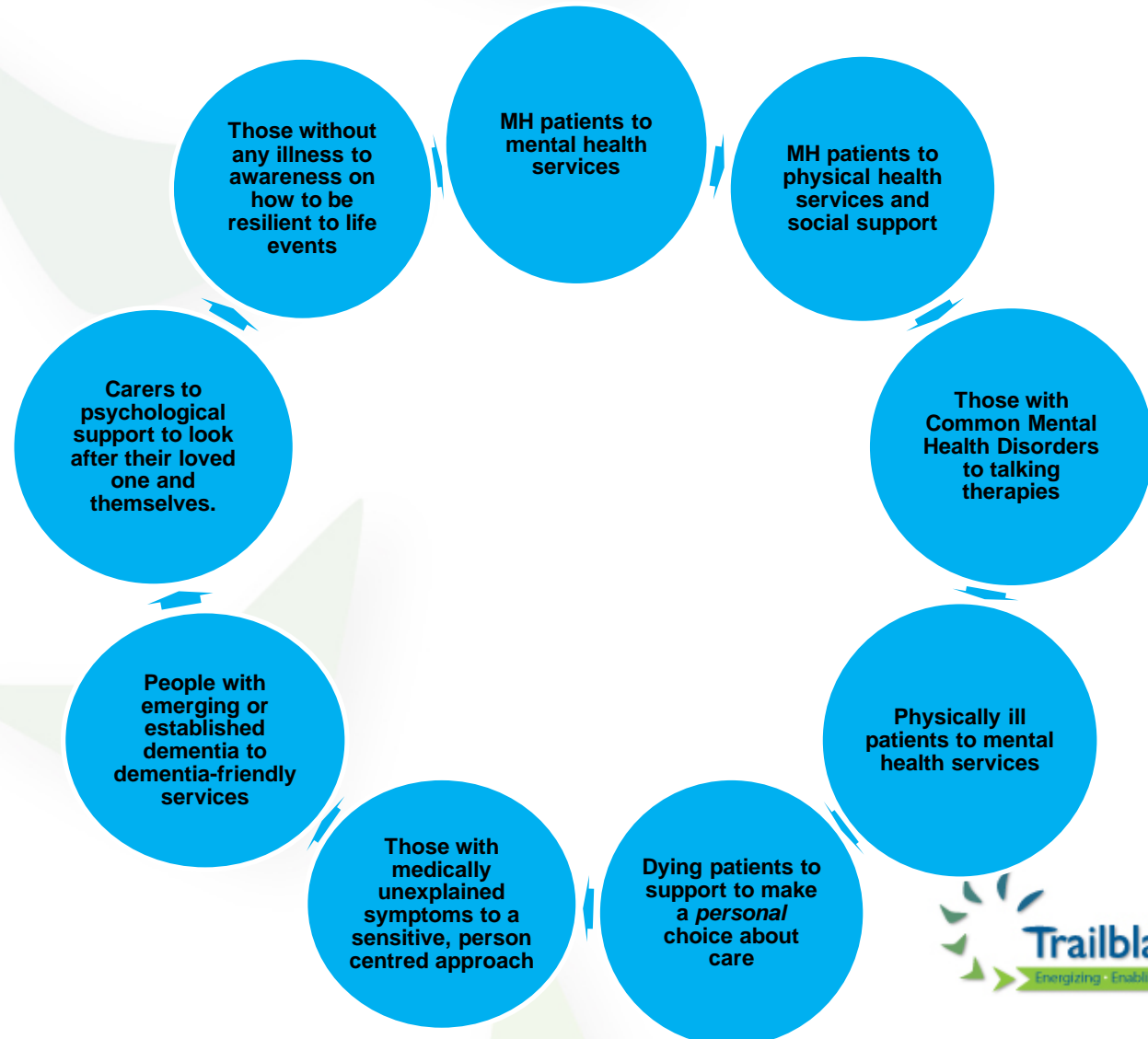
The world offers itself to your imagination,

Calls to you like the wild geese, harsh and exciting -

Over and over announcing your place

in the family of things.

Access – how well do we do?



3 key themes

- **Meet the patient where they are**
 - Making that connection is critical to everything
 - *Feelings* are more important than facts
- **It's a story – a story that should make sense**
 - To public, patients, family, clinicians, managers
 - Listen to *their* story; tell *your* story
- **Set outcomes - for well being**
 - for improvement, hope, recovery, esteem, belonging, love, attention, safety, health
 - Where you *want* to be
(not where you don't want to be)

You can't really get to know a person until you get in their shoes and walk around in them.

Meet people where they are

➤ What is it?

- Their context is important
- Health may not be their top priority
- People have ideas and beliefs
- Organise care to make it easy for them

➤ Enablers

- Listening
- Open questions
- Start at the beginning
- Focus on the impact

➤ Barriers and Pitfalls

- Systems that put the professional first
- Professional uncertainty and fear
- Commissioning service outputs
- Stigma
- Lack of evidence

➤ Top Tips

- Acknowledge the distress

**People will forget what you said,
people will forget what you did,
but people will never forget
how you made them feel.**

A narrative that makes sense

➤ What is it?

- The patient's story
- Our own story
- The public story – context
- Feelings are more important than facts
- It is honest

➤ Enablers

- Focus on symptoms and function
- Continuity of care
- Board narratives

➤ Barriers and Pitfalls

- Focus on a diagnosis
- Dismiss the symptoms
- Imply there is nothing wrong
- Assume you know what is wanted
- Enforce psychological explanations
- Telling the story over and over

➤ Top Tips

- Take time
- Share decisions & uncertainty
- Avoid jargon

*The real voyage of discovery consists
not in seeking new lands,
but in seeing with new eyes*

Outcomes

➤ What is it?

- Patient centred
- Recovery focussed
- What you want (more of)
- It is gradual and continual
- It is holistic
- Builds on the patient's strengths

➤ Enablers

- Define goals with the patient
- Let them monitor and report progress
- Being clear what you want – say it!
- Provider partnerships

➤ Barriers and Pitfalls

- Focus on numbers & targets
- Focus on reductions
- Research based commissioning (esp. pharma)
- Outcomes can be difficult to define and measure
- Aspirational paucity

➤ Top Tips

- Outcomes motivate teams
- Outcomes win support

**Not everything that can be counted counts,
and not everything that counts can be counted**

Access

System focus

- Starts with the doctor – what suits them
- The default is gate-keeping, waiting, and done “our way”
- Based on buildings
- Regulators interested in processes (staff, beds, money)
- Missed appointments are the patient’s fault
- Chaotic lifestyles are blamed for non-compliance
- People are ‘hard to reach’

Patient centred

- Starts with the person
- It listens and hears.
- Is about flow and enablement
- Seeing someone who cares and wants to get to know you
- Is easy for the patient
- Services ensure patients are helped, informed, reminded
- Considers the individual’s needs and challenges
- It is proactive – searches out those who are ‘easy to ignore’
- It is bothered.

This bad and hard and tough enough, so please speak like a human, make it better not worse

The future of access...

- ❑ **Kath** gets 24 hour care in her home, because health and social care pool their budgets. Mental health services arrange for the Alzheimer's society to spend time with them both. The paramedic pops in once a day, and helps train care givers in simple techniques - better than an average of 5 "999" calls a day.
- ❑ **Mandy** is seen proactively every week by her GP. She carries her copies of previous CT scans and a letter from her GP about her condition. She can book online
- ❑ **Grant** can be seen by the same GP on the first appointment of the day so he is never kept waiting. His GP talks to other specialists rather than referring to them
- ❑ **Billy** meets someone who is bothered about him every day, someone who reassures him about his voices. Someone who helps with his skin sores, and his incontinence, his cough and his smoking.

The secret of caring for the patient is to care for the patient.

We cannot do *everything*, and there is a sense of liberation in realising that.

This enables us to do *something*,
and to do it really well.

Oscar Romero



**So when the caged bird sings with a fearful trill
Of love and hope, longed for still,
Have I heard that cry on my distant hill?
Have I opened that cage to freedom?**



Things that have worked for us...

- Online booking
- Online and telephone consultations
- Web based support
- Linked records access
- Follow-up by the GP
- Continuity of care
- Apps to help with anxiety and other self-management
- Patient held / accessible records
- Psychotherapy early on as prevention
- Relatives get support as well
- Alzheimer Cafes
- Dementia navigators
- Experts by experience / buddying
- Mental health staff in A&E and on wards
- Weight management, smoking cessation, exercise therapy as a routine; as a positive intervention
- Employers with understanding
- Communities aware of MH First Aid as much as they are about physical first aid