People's pathways into hospital range from being well planned to being sudden emergencies.

GP HOME VISITS

Lack of resourcing/

incentives for the After

putting strain on people

trying to manage at home.

Hours GP service is

THE COMPLEX GUILT OF ILLNESS

Older people have often been carers themselves and may have built an identity around being a breadwinner, a carer, dependable, reliable and a supporter to their friends and family.

The health issue they are experiencing may be overshadowed or exacerbated by the uncertainty of what this illness will mean for their role in the family.

GAP

GAP

waited 7 hours for the after-hours GP to do a I call an ambulance home visit. We didn't want to or should I wait for the pain go to ED, but his situation to pass? What's in my health was worsening! plan? What am I covered

I felt so overwhelmed and confused when my mother needed a GP at home and we could not get one to come.

can I lessen the stress on my loved ones? I don't want my family to know I'm unwell because I don't want

them to worry about me. the accident I was thinking, 'How could I be so stupid? I've been using powertools for 40 years. My family aren't

going to trust me now this

has happened.'

My GP explained the risks and benefits of surgery. It was going to be very risky at my age so it was important I felt in control.

Why do I have to go urgently? What's wrong with me? How long will I be away from home?

over their situation and

Lack of literacy around

emergency may deter

at the right time.

people from seeking help

their choices.

FEAR, RISK, CHOICE UNCONSCIOUS BIAS AND INFORMATION

Older people are aware layer of inhibition about of the increased risk hospital for Aboriginal of complication during people - encountering procedures at their unconscious or conscious age, but clear and frank discrimination from staff / conversations about these people in any institution or risks gave people a sense of confidence and control

Pre-Hospital

Fears of encountering discrimination and 'being treated as a second class citizen' in care can care plan coverage in an exacerbate stress levels with a health issue.

most important

thing for me was ensuring my

dad was treated with dignity and

respect as an Aboriginal person,

and not regarded as a second

class person.

DECISION MAKING

There can be another When at home deciding what action to take, having a health professional to can advise on severity of symptoms can add confidence to a carer

unsure about encouraging someone out of their comfort zone if they are Trusted relationships people have with health staff in community are crucial to getting people

TIMELY & SUPPORTED LANGUAGE BARRIERS

There is a therapeutic effect to feeling heard.

People with a language barrier can perceive GPs and staff as intentionally ignoring them.

A holistic approach to what a person needs in the moment can go a long way. A GP stepping outside a strictly clinical role and assisting a person with transport options smoothed their journey.

care at the right time.

Having a doctor listen was more important than the actual examination.

hospital I was thinking

doctors are all in it for the

money and even experts don't know

everything. But the GP bulk billed

me and the hospital staff were

kept saying she was OK and didn't want to go anywhere. The OT made the decision we should go.

I was reluctant to call an ambulance so my daughter called the Healthline Nurse to get advice. Had

a lot of contact and advice from my pharmacist before diagnosis.

Being made to feel relaxed about the procedure was so important.

family GP saved me lots of time and confusion in the hospital by preparing my medical notes thoroughly before I went.

ANNED ADMISSION

People receiving a call for st minute was difficult.

MERGENCY TRANSPORT

First response teams are in a great position to provide onfidence, information, advice and support to the person and

dementia and travel is difficult.

RURAL AND REMOTE TRANSPORT

Transport and transfers for

The

paramedics were fantastic, they gave me so much confidence when I had none. They really listened.

Anxiety and confidence matters: The levels of certainty or uncertainty people experience in their journey impact their ability to focus on their health goals.

Throughout

it all, being well

informed of what was ahead

helped me feel more in control

and not fearful.

doctors were

informative and answered

my questions so I felt at

ease.

can't I wait for

surgery at home rather than

occupying this hospital bed

for 3 days?

During Hospital

GRIEF, SHOCK AND LOSS

health issue.

Things can change

suddenly for someone

in full health at the peak

of their life and career. I

they appear older, they

may be treated as if this

situation should come as

aspects of a life changing

There

was no recognition

of emotional/mental state

for the patient in ED.

I had

a major dip in

confidence prior to surgery

because a cardiac anomaly

was discovered. It really

shook me.

no surprise. Emotional

illness need to be

considered,

GAP

Not all older people are in

hospital for an age-related

urgery the evening before the pointment found transport otions difficult. The community ansport service requires two days notice for booking. For eople living alone, arranging ansport and pet-sitting at the

nergency transport options other than ambulance can be hallenging, especially when the person is resistant to going o hospital, or if a person has

rural and remote people to see specialists or get to hospital is a challenge. In addition, if they have family members or carers travelling with them, accommodation is a challenge

CARERS ROLE GAPS IN ED

wait might be.

GAP

Hospital is

not really a 24 hour

service. We only got a proper

diagnosis in the daytime with

senior staff.

doesn't somebody

listen to us? My daughter

is in so much pain she couldn't

speak and when I tried to speak

for her I was ignored.

[Language barrier]

Levels of uncertainty. concern, stress, pain and fear are their highest in ED. Exacerbated by long wait times and no

indication of how long the Feelings of heightened anxiety and being ignored. Some people felt their health condition was being overlooked or handled

There may be grief, fear and loss wrapped up in the sense of duty expressed by a spousal

Family/carers are often very invested in, and dedicated to, helping. They see themselves as an important part of the may have been in a full

anyone.

wife's health

condition was completely

overlooked by inexperienced

junior doctors in ED.

Twice.

during long wait times and other uncomfortable situations in hospital. working care team. They time support role at home and feel they understand clumsily by 'junior' doctors the person better than

COMMUNICATION = STAND-OUT STAFF CHOICE = CONFIDENCE

People and carers notice Clear communication when staff are 'in the throughout all interactions, moment', focussed, and efficient. Watching staff changes and processes helped to elicit a sense of work in a thorough manner confidence and control in makes people feel safe people. This confidence and confident (however was linked to a greater the inverse is also true.) resilience and patience

respect

Mum is

deaf and was using

a child's toy to communicate

with the doctor. I was happy to

see the doc was willing to

Constant

monitoring and

communication from staff

was great. I cannot see that

anything was missed.

Qualities associated with positive experiences: Attentiveness

 Thoroughness Efficiency Answering questions Being treated with

APPROPRIATE SUPPORT **ROLES AVAILABLE**

People also struggled

available.

hospital like using pads to Roles such as the toilet can take on a whole Aboriginal Liaison Officer emotional dimension for older patients, as for them need to be available to it may symbolise a loss of serve the diversity within independence and dignity. a population when they need advocacy and support the most.

> caring for loved ones with Some people were dementia alone in the able to access ward with no ward carer transport organised by the ambulance service which greatly improved

was very confused

don't know how she could have

advocated for herself if I wasn't

understand at all.

as to what was going on.

She did not cope well with the pads toileting, especially not when she was alone.

It really meant a lot to me to be taken in a wheelchair out for morning tea out of the room because I couldn't walk. This really mattered to me.

DIGNITY

Something which is

common practice in

there. I thought a dementia carer would come. wondering if there would be an interpreter. if not, I won't be able to understand the

use the toy. The nurses were chatting meal order. and distracted, they were not focussed on the patient. There was a poor handover and they used the wrong charts.

wanted to see the Aboriginal Liaison officer and I had to wait over 24 hours. I had to ask so many times about it. was thinking, are they listening to me?

TRANSPORT /

People had a sense of feeling dropped out of clinical care once they exited the hospital doors. This was in part due to transport options and in part due to a lack of clarity about next steps in

their experience. Most people had no awareness of their

Travel can be stressful, especially for single people with no family or friends to call on.

support systems available to them, and sometimes fragmentation disrupts the process that would otherwise connect people with service providers who could

grateful to the ambulance service organising travel for me. I had no way of getting home.

There is a gap in

transport options.

Not all people have

CONTINUITY OF CARE

GAP

continuity of care. People need to know what ongoing options are available to them and have the literacy and support to know how to access them.

support people on their journey.

Smooth information sharing is critical for the ongoing health journey and to lesson the likelihood of people reappearing in ED.

People may or may not know to contact the GP

GP FOLLOW UP

Primary care needs access to the right information at the right time to

DISCHARGE NOTES

Ongoing wellness for a

long life was top of mind

for people upon leaving

hospital. They want to

be confident they are

for themselves at home

with food, medication,

follow up, etc.

instructions.

discharge

hospital were poor. Especially

medication instructions.

I don't

have any discharge

notes, I don't know what

foods to avoid...who can I call

to ask?

summaries we got from the

activities, appointments

People want more clarity

comprehensive medication

l was

heavily involved

with Dad's discharge. I was

his eyes and ears, listening

to all the advice and

information.

asked for written

instructions and an

explanation for medication on

discharge. Doc just gave

me a list.

from their discharge

notes, especially more

making the best choices

for follow up care. People organising appointments and follow ups often may or may not have a GP, and are only realising became the responsibility after a crisis they need to of carers in cases where people did not have a find one. private consultant/ home Primary care needs access to the right care package provider information at the right / advisor to forge an ongoing home care plan time to support people on

their journey. People trying to manage at home (and who had difficulty leaving home) needed GPs to come to the home.

never had a good

GP. But now we've

one.

realised we really need

AHEAD

Self advocating and

CONTROL

Post-Hospital

There is a strong link between people returning home and feeling more calm and in control. Factors include:

own bed own food

HOME, STABILITY.

controlling own sleep patterns

grandchildren and great grandchildren visiting the home helped to lift spirits and wellbeing

LIFE IS DIFFERENT HOME CARE ROLE OF FAMILY AND FRIENDS

Family and carers are forming the main home care team for people leaving hospital, fulfilling many different roles to ensure people are supported

Once the physical emergency has been resolved in hospital, there often lies in wait a tough emotional process of

re-learning how to live and coming to terms with and cared for in their own loss (of independence, purpose, identity, other). Grief, shock and loss: consider the emotional

aspects of a life-changing illness or injury and the support and literacy required to stay well.

most important

thing for me was that we

had a care plan and follow up

appointments locked in from

the consultant who had long

term care for us.

Knowledge

of the system and

what was available to me (eg.

contacting the QML Anglicare

GP) really helped me feel

in control.

home made me feel more in control. When I was friends for total support home, I was more emotionally after hospital. stable, and I was able to heal better.

neighbours who keep an eye on me. I can call on friends because family is interstate.

home I was relying on friends and family for my care, feeding and homecare chores.

nospital was health awareness for continued wellbeing.

most important

thing for me when I left

the accident, my

wife and I now put personal

safety above all else at home

It's part of everything we

do and think.

have wonderful

Once I realised I couldn't

work anymore, I was so angry. Having others do jobs used to do (lawns) makes me feel less independent.

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