

#TalkMore

Lucy was very inspiring

Thanks so much for such a helpful introduction to jamboard

Hello

Hi everyone, great start to the day :)

Hi all, inspirational start to the day

Lucy was so inspirational!!

Hello

hello

Hi Everyone!

Its all very well preaching to the converted, but what about the activists who fight against it?

hi



CATALYST
Igniting new Ideas

aqua
Shape Change Inspire Quality Transform Care



Great start as ever with R&D NWest

Hello :-)
thank you for a great start

JUst testing

This is too good

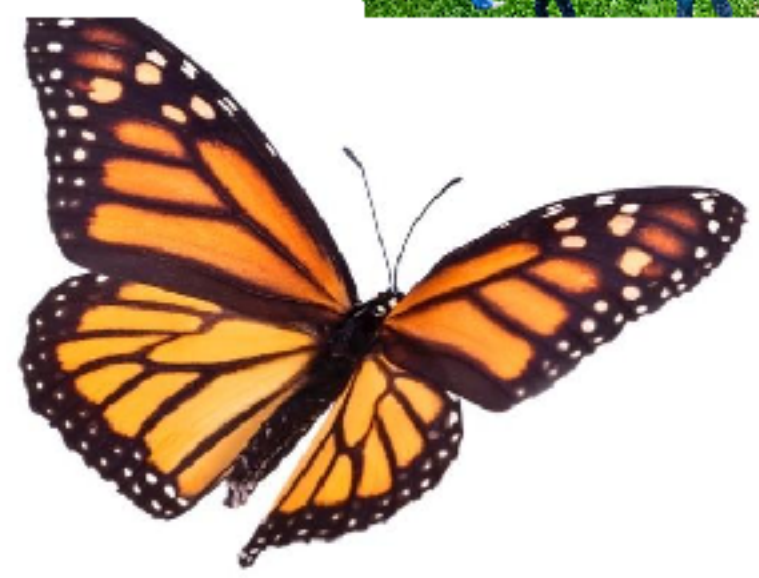
Welcome

Circle



Roles

Law



a click

...mouse and click to go somewhere you can

Principles

Law
Foot

A click

Whatever happens is the only thing that could happen

Whoever comes are the right people

IF you Find yourself in a Situation where you are neither Learning nor contributing use your two Feet and go somewhere you can.

When its over its over

Shall we talk more
about death and dying?

AGENDA WALL

Breakout Room N
Breakout Room I
Breakout Room M

Breakout Room O

Breakout Room G

Breakout Room A

Breakout Room B

Breakout Room C

Breakout Room D

Breakout Room E

Breakout Room F

Session 1
12.45

How are we going to prepare the next generation to talk about death and dying. Convenor's name Manisha

Why is there a difference between how we support children vs. adults at the end of life, and what can be learned? NIGEL

How do we support a palliative patient who lacks capacity? Laura Mercer

What can we do about the disability lobby who see this as a threat? Martin

How do we make having conversations about death and dying everyone's business Liz

How can support minority groups to raise conversations about death and dying? Convenors name Frances

Session 2
14.15

How can we have death positive conversations within wider society, with school age children for example Kayleigh

How do we ensure people have the confidence and skills to talk to people with a learning disability about end of life? Convenors name: Frances

How do we support people to live alongside palliative care? Convenor's name: Connie

How can we change the narrative by talking about Future Care Planning rather than ACP? Trisha

acute care v's ACP/future care planning in an acute episode. Emma Given

Should we talk about death earlier with people? Philip



NEWS WALL

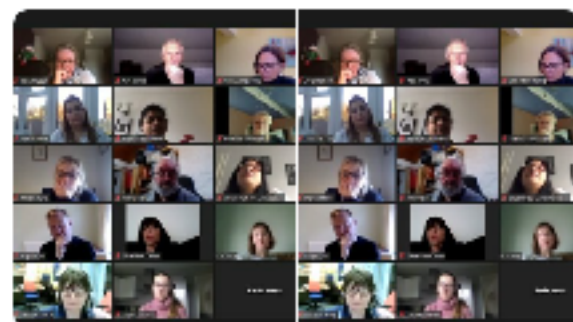
Our reluctance to honestly examine the experience of aging and dying has increased the harm we inflict on people and denied them the basic comforts they most need.

Atul Gawande

"We need to have the courage to face death" Lucy



🔄 @NHSNWRD: RT @kbarnett2019: And we are off with our #talkmore event! @Aqua_NHS @NHSNWRD @kevwyke. We are hearing from @LucyAlexandria about her experiences of ABOL conversations



Kev Wyke @kevwyke · 3h
Should we talk more about death and dying?"

Co-facilitating @Aqua_NHS @NHSNWRD Virtual Catalyst Open Space event today...Fascinating subject for some important conversations. #talkmore



Kayleigh Barnett @kbarnett2019 · 1h
Takeaway messages from @LucyAlexandria 1) empower patients to #talkmore 2) flip the ownership of dying. Give death back to its rightful owners 3) its OK to show emotion with your patients, it shows your invested in their lives 4) always ask what's important to people



"Give me control" Lucy

"Talking about death doesn't make it happen" - Lucy Watts

Some inspiration...
<https://www.leapfurther.org/catalyst>

**Session 1
Room A**

How are we going to prepare the next generation to talk about death and dying. Convenor's name Manisha

Key Points

1 How to educate staff to deal with death and dying?

Fear in practitioners- Removing hope from patients life

In secondary care - assumptions made that patients know about their condition and prognosis

Increase in end of life in younger generation

Unrealistic expectations

Fear of using the word cancer- often associated with death

Be open and honest

Next Steps

Need to empower staff to lead the conversation

Sage and Thyme sessions for newly qualified

Communication session for post reg staff

National campaign about Dying matters

Advanced care planning

Prepare families and carers

Build confidence in staff

Simulation and case studies

Need cultural shift

Huge issue- need support from management

Session 1
Room B

Key Points

Next Steps

Why is there a difference between how we support children vs. adults at the end of life, and what can be learned? NIGEL

Patients with cancer have palliative care teams, but other adults generally don't have special end of life teams etc.

Anticipation and advocacy, i.e. if parents absent for whatever reason - we still undertake the different care rituals even if we've not been asked directly to do this - but sometimes appreciated later on by family

Different (more) resources available to support children/families at end of life, i.e. expectation of this.

Not enough time available for end of life care in adults compared with children

Culture of neonatal care >> policy >> guideline, but it's the culture that tends to guide peoples' behaviour

Perception of different age groups - end of life care 'expected' with older people, "He had a good life"

Can we standardize our approach? Does this conflict with working in an individualized way?

How can we stop ticking boxes, e.g. giving the bereavement leaflet is not enough

Sharing good practice ("Lock of hair" example)

Bereavement box - use ideas and practices from childrens' end of life care >>> apply to adult care.

**Session 1
Room C**

Key Points

Often early conversations around dying are rejected by patients and family

Cancer and dying is more talked about rather than long term conditions e.g COPD, Dementia, MS and MND, stroke

Misguided expectations from a healthcare professional

Hospital is an unfamiliar environment for these patients

Lack of equity with patients care depending on level of capacity

Lack of knowledge and courage from healthcare professionals around palliative care and dying

Relying heavily on the family members to make decisions

**How do we support a palliative patient who lacks capacity?
Laura Mercer**

RESPECT forms

Patient's diagnosed with Dementia need early discussions around EOL whilst they still have capacity

Capacity is a big factor in equity

Difficult to determine the patient baseline mobility and cognition

Poor patient compliance

More funding for dementia patients

Community services need more services/time towards preventing these admissions. And more MDT working

Dementia is often diagnosed late

Reactice approach rather than proactive approach

Unpredictable patient behaviour. Can differ from day to day

Lack of consistency in the knowledge between staff. Particularly around dementia

Haven't got the time for these patients in an acute setting

Better GP services. More appointments available

More staff required to support these patients

Convenor:

Participants :

**Session 1
Room D**

Key Points

What can we do about the disability lobby who see this as a threat? Martin

It is so difficult to deal with disable people and it is hard for family to accept the truth

Only me. This is an issue which is external to health services. It's not obvious what anyone can do but its part of the problem of not talking about death.

Next Steps

**Session 1
Room E**

Key

Different aspects of conversations:
Dying process;
'after' death what happens;
practicalities

Death cafes for carers - of all sort- would help

society change - are families prepared to help with the conversations.

education - what are the barriers and how do we support?

Build comfort zone

always some people who never want to discuss death. its all about choice.

Patients would like to have the conversations - opening the door for them

How do we make having conversations about death and dying everyone's business
Liz

Next Steps

Spirituality /culture /what gives someone meaning in their lives and its impact - not sure about getting involved - important element - any concerns - support in caring for those patients

cultural change around death over the years

building confidence

communication skills training

COVID may be a good base to start - change a mindset in society - can happen to anybody

Early conversations so we know their wishes, individuality - can't do that if we don't know them. Do before they transition into EoL - timing when is the correct time

death cafe for students to get them more comfortable in having conversations about death and dying

death cafes - do they help promote conversations around death and dying - relaxed - no judgement - needs more promotion - how do people know about it

case studies and lived experiences - examples to people

split into different components - the dying process - practicalities - not one conversation one of many

Convenor : Frances

Participants :

Next Steps

Key Points

**Session 1
Room F**

**Brief
intervention -
grasping the
moment**

Who is their support network? Do they have someone to support them after conversations have happened?

**How can we
make
palliative care
accessible to
all?**

Go to the right places to have a conversation- find out where communities gather and go there to speak to them

**How do
we reach
the hard
to reach?**

**Enable
people to
access
services**

1 size doesnt fit all with EOL care- we need to build services that work for different people in different circumstances

Where are the communities that we dont reach getting their information from right now?

**Who else can
be having the
conversations
with minority
groups? Soup
kitchens etc?**

**Grasp the
moments that
open up a
conversation**

Utilise simulation to educate in how to support minority groups

**Taking the
conversations to the
people, not waiting
for patients to start
the conversations.**

**How can support
minority groups to
raise conversation
about death and
dying? Convenor
name Frances**

How do we plant the seed and then let them germinate, being open to have the conversation when they've had chance to reflect on it

**homeless,
travellers,
boat people,
people with
learning
disabilities.....**

How do we start a national campaign to improve conversations with communities

This gives access to all different cultures, and backgrounds, and gives them the opportunity to see it from other perspectives as well

**Education of
faith leaders
etc to
empower
them to start
a conversation**

**Make it
everyone's
responsibility**

**Can we go to
their locations
and start the
conversation
with them?**

**Frances,
Connie
and
Kayleigh**

that the 'right' people are in the room at the 'right' time- whoever is right for that person- It might be a religious leader, it might be a parent or spouse, or it might just be a pet for comfort. What is right for them, is what is

How do we empower staff to feel comfortable in different situations with different groups of people? It's hard to engage people if the staff aren't confident and empowered themselves

We need to talk about it much earlier- most minority groups will still go to school at some point. If it's on the curriculum they will have the opportunity to talk about it

How do we make sure that we are ready to have a conversation when THEY are ready

**PHSE is the
perfect place
for this**

**Ask what is
important to them-
we are all people
whatever 'group' we
might belong to**

**Look at overcoming
the barriers to
access services and
enabling everyone
to have
conversations**

Convenor : Kayleigh

Session 2
Room A

Key Points

How can we have death positive conversations within wider society, with school age children for example Kayleigh

'Celebrity' Dr's- Dr Ranj, Dr's Van Tulleken, Dr Ravi Jayaram (paediatrics)- how do we get them to start talking about it?

Aparna, Dawn, Linda, Manisha, Jo, Nigel, Debbie, Sheridan, Emma, Stacey

Age appropriate public campaigns- GMB. This morning, Loose Women, The One Show etc for adults, Blue Peter, News Round etc for children

More than one conversation that is ongoing

Conversations will change over the years- the conversation you have with a 3 year old will be very different to the conversations we have with a 17 year old or a 77 year old

Some people in society might never want to get involved in those conversations

If people have questions then we need to be answering those in a sensitive and appropriate manner for that time and place

Is there an appropriate age to talk to kids about death and dying?

Or are there age appropriate conversations to be having?

How have we done this with other things that used to be taboo?

We can do as much damage as we do good if we approach things in the wrong way

Once you open the floodgates with children you have to be prepared to have all of the conversation

Are we giving people the right information when talking about PPD? Most of us would immediately say we wanted to die at home but is the reality very different?

Is the preferred place of death being enabled but the experience is being impacted on because of stretched resources

Can we capitalise on Covid for improving conversations about death and dying?

Covid is allowing us to be less risk averse about enabling people to die at home with more complex symptom management- Is there enough resource to support the community services?

What is the patients experience of dying at home?

Be open and honest and make it really accessible

We need to communicate it extremely clearly and check that people have understood what we have explained rather than what they think we have said

Remove the fear by normalising the conversations

Can we make death cafes child friendly?

We have to accept that some people will never want to have those conversations and we have to be ok with that

BOOKS FOR CHILDREN- reading can help stimulate conversations. It doesn't have to be specific books either. Roald Dahl, Harry Potter, His Dark Materials all concentrate on elements of death and dying. Use them to

Themed week at school (whole school activity) on death and dying- each school year does something on the topic in an age appropriate way

How do you plan for EOL care when people just don't want to talk about it?

What lessons can we learn from the 'switch' in talking about cancer to take to improve conversations about death and dying?

Scouts, beavers, rainbows, dance class etc- how can we open conversations in these settings?

Signposting people to resources that can help- death cafe. living wakes etc. Helping people to know that things exist will help them to access it when they are ready to

We have to be careful to make it inclusive

Do we need to 'politicise' death and dying conversations to make it important to people- Do we need to make it about peoples rights to have the death they choose, in order for people to be willing to talk about it?

Once we start having those conversations they become more natural and easy to have

Next Steps

Convenor : Frances

Participants :

Key Points

Next Steps

**Session 2
Room B**

More joined up services communicating the needs of the patient with learning disabilities - taking a holistic approach

More opportunity to talk from an earlier age using prompts they are interested in.

Proactive discussions around disease progression

Make reasonable adjustments, ensure the environment and time in appropriate

Who's responsibility is it to have conversations?

**How do we ensure people have the confidence and skills to talk to people with a learning disability about end of life?
Convenors name:
Frances**

Behaviours can be communicated differently dependent upon the environment

confidence around how to assess capacity

First priority is communication and finding a way to communicate with the individual.

Discharge - making sure those that will be caring have the knowledge, skills and confidence to care upon discharge.

fluctuating metal capacity - element of repetition

family shield people with learning disabilities making death a taboo

Access to services and entitlement to further referrals.

Earlier conversations from diagnosis

educating people with learning disabilities about what does death mean

Convenor :

Participants :

**Session 2
Room C**

Key Points

**Focus on
quality of
life**

**Important for
patients to
know they
have a choice
about their
care pathway**

**Goal
setting/motivational
interviewing**

**How do we support
people to live along
side palliative care? :
Convenor's name:
Connie**

**MDT
involvement**

**Connotations of
'palliative' care -
should we be calling
this something
different?**

**Giving
patients
education and
options**

**Quality vs
quantity**

**Goal setting - what
does the patient
want? Do they have
things they want to
achieve?**

Next Steps

**Staff education on
initiating these
conversations and
how to respond**

Convenor : Trisha

Participants :

Key Points

Next Steps

**Session 2
Room D**

everyone's
responsibility

**ACP
medically
driven**

can only have
the
conversation if
someone
wants to have
it

**How can we change
the narrative by
talking about Future
Care Planning
rather than ACP?
Trisha**

Life plan
conversations,
rather than
advance plans

building
confidence to
have the
conversations

**A life
journal
given at
birth**

Normalise the
conversation

staff need
permission to
have the
conversations,
not just one
persons job

Should we be
using the
words Care
Plan?

life journal
completed by
the person as
individual to
them

**society
driven**

choose the
moments,
taken from
comments
and cues

education and
training to
empower staff

Convenor :Emma Given

Participants :Liz, Toni, helen, connie, Manisha

Key Points

Session 2
Room E

acute care v's
ACP/future
care planning
in an acute
episode.
Emma Given

stop consider
death as
failure but
what can
enhance time
left

is acute care the
best place to have
these
conversations?

positive experience
and what matters
most to the person
as oppose to
continue to treat
regardless

Poor
communication
from the acute
setting to the
patients and
families particularly.

recognising
when
someone is
dying

what can we do to
support dying
patients in acute
care, with COVID
restriction? hand
held hearts, face
time

Next Steps

do we learn
from went
well rather
than react to
what doesn't
go well.

regular
conversations -
assessments like
health screening
regarding what are
your preferences

review visiting
in hospital -
especially
with COVID

should we
collect more
information
after death

education and
training for
staff and
patients and
families

dedicated to
team to
collect all info
on what's
important to
the patient.

palliative care
in acute areas
to support

Convenor :

Participants :

Session 2
Room F

Should we
talk about
death earlier
with people?
Philip

Flag up Postvention
Assisting those
Bereaved By Suicide
(PABBS) course run
by Suicide UK

Key Points

Accept that death
comes to us all - it is
inevitable. Don't try
to shield people
from it

Difference in
expected vs
unexpected death -
difficulty when
death is for example
suicide and no
conversations have
been possible.

Important that
wishes are available
to others eg
through ambulance
service - but if its
not in place they
cant act on them.

Conversation at a
time people are well
enough to fully
engage - not put off
till the final hours /
minutes

Use of role play - for
nursing students to
see how best to
break the news to
the family

Integrating records
to say what peoples
wishes are -
example Salfords
Integrated record -
option to share with
GP, hospital etc.

When you get
a diagnosis
should the
clinician talk
about
prognosis

make it much easier
for people to record
their wishes, and to
have them
somewhere central
like the Greater
Manchester Care
Record

Friends mum died in
hospital and nurse
with them opened
window 'to let her
spirit out' - not pre
negotiated - she took
peace from this but
someone else might
have been offended

Next Steps

Hospitals
should admit
that they have
a mortuary

Availability of app or
online central
repository for last
wishes - could link
to care record.
Prompts to flag
what sort of things
people should
consider

