COVID 19 Palliative Care and Anticipatory Care Planning

- Libby Ferguson libby.ferguson@mariecurie.org.uk
- Jude Marshall
- judithmarshall@nhs.net

Topics

- Experience so far
- Where are people dying from COVID 19 in Glasgow?
- Symptom control and anticipatory prescribing
- Syringe drivers and contingency plans for alternatives
- Communication – tc and vc
- ACP in care homes
- Oxygen
- Support available

COVID Deaths GG&C NRS 3/6/20

	COVID	All cause
Home	57	2005
Care Home	589	2103
Hospital	612	2828
Other institution	4	17

End of Life Care Guidance when a Person is Imminently Dying from COVID-19 Lung Disease

The focus of this guideline is to reduce the suffering for those dying from COVID-19 lung disease.

- A proportion of patients dying of COVID-19 lung disease could have severe symptoms with rapid decline. In this situation it is important to deliver effective medications, at effective doses, from the outset. Early management of symptoms will be the most effective way to reduce suffering.
- The clinical profile of COVID-19 lung disease driven dying is likely to include:
- High breathlessness / 'air hunger'
- High distress
- High delirium / agitation
- High fever
- Risk of cessation of life over a short number of hours.

This guideline should only be used when reversible causes for deterioration have been addressed and there is consensus that the patient is dying.

Atypical presentations

- Less likely to present with cough, breathlessness or temperature
- Delirium
- Anorexia, fatigue, malaise
- GI symptoms
- Deterioration in function
- Falls/ syncope
- Day to day variability

Anticipatory Prescribing in COVID

- https://www.palliativecareguidelines.scot.nhs.uk/guidelines/symptom-control/end-of-life-care-guidance-when-a-person-is-imminently-dying-from-covid-19-lung-disease.aspx

Breathlessness

Consider whether the patient is benefiting from any oxygen prescribed. If not, consider discontinuing non-beneficial oxygen and using medication and non-pharmacological measures for symptom control.
Patients who are receiving medication via nebulisers may continue to do so in the context of COVID-19 lung disease. Currently corticosteroids are not recommended for managing the symptoms of dying of COVID-19 lung disease.

Non-pharmacological measures to manage breathlessness should also be considered, these include positioning, relaxation techniques, wiping the face with cool wipes.
Fans must not be used in the context of COVID-19 infection as they increase aerosol spread of the virus.

Breathlessness Early commencement of syringe pump, if available, is strongly recommended			
Morphine sulfate	Subcutaneous or slow intravenous injection	Start with 2 to 5mg as required; can be titrated to resolution of symptoms.	•Titration frequency: subcutaneous 10-15mins; intravenous 3-5mins. •Consider using the higher dose if the patient is very distressed with breathlessness. •Consider using lower doses in elderly patients. •In patients who are already receiving regular opioid, use 1/6 of total daily opioid dose for as required dose.
	Subcutaneous infusion	Start with 10 to 20mg over 24h.	
Midazolam	Subcutaneous or slow intravenous injection	Start with 2 to 5mg as required; can be titrated to resolution of symptoms.	•Titration frequency: subcutaneous 10-15mins; intravenous 3-5mins. •Consider using the higher dose if the patient is very distressed with breathlessness. •Consider using lower doses in elderly patients. •Maximum dose 100mg over 24h.
	Subcutaneous infusion	Start with 10 to 20mg over 24h.	

Cough			
Morphine sulfate	Oral	5mg every hour as required	•Consider using lower doses in elderly patients. •In patients who are already receiving regular opioid, use 1/6 of total daily opioid dose for as required dose.
	Subcut injection	2mg every hour as required	
	Subcut infusion	10 to 20mg over 24h	
Codeine linctus	Oral	60mg every 6 hours as required	
If the patient has known renal impairment (eGFR <30), consider using equivalent and equipotent doses of oxycodone, if immediately available, as required and alfentanil or oxycodone in an infusion. Refer to: https://www.palliativecareguidelines.scot.nhs.uk/guidelines/pain/choosing-and-changing-opioids.aspx for conversions. If only one opioid is available, this should be used to relieve suffering in the setting of COVID-19 lung disease rapid dying.			

Respiratory secretions

Hyoscine Butylbromide	Subcutaneous injection	20mg every hour as required	•Alternative drugs and routes of administration are also available – Refer to: https://www.palliativecareguidelines.scot.nhs.uk/guidelines/symptom-control/alternatives-to-regular-medication-normally-given-via-a-syringe-pump-when-this-is-not-available.aspx
	Subcutaneous infusion	Up to 180mg over 24h	
Glycopyrronium	Subcutaneous injection	200micrograms every hour as required	
	Subcutaneous infusion	1.2mg over 24h	
Hyoscine Hydrobromide	Subcutaneous injection	400micrograms every hour as required	
	Subcutaneous infusion	2.4mg over 24h	

Terminal delirium / Terminal agitation / Terminal restlessness			
A combination of midazolam and levomepromazine should be considered in terminal agitation/restlessness/delirium.			
Early commencement of syringe pump, if available, is strongly recommended.			
Midazolam	Subcutaneous or slow intravenous injection	Start with 2 to 5mg as required; can be titrated to resolution of symptoms.	•Titration frequency: subcutaneous 10-15mins; intravenous 3-5mins. •Maximum dose 100mg over 24h. •Better for agitation due to distress and anxiety. •Consider using lower doses in elderly patients. •High doses may be required in patients who have severe agitation.
	Subcutaneous infusion	Start with 10 to 20mg over 24h	
Levomepromazine	Subcutaneous injection	Start with 10 to 25mg every hour as required	•Doses over 100mg/day may be given under specialist advice. •Better for agitation due to delirium. •Consider using lower doses in elderly patients.
	Subcutaneous infusion	Start with 50mg over 24h (can be given as bd injections)	
Haloperidol Use where levomepromazine is not available.	Subcutaneous injection	1mg every 2 hours as required.	
	Subcutaneous infusion	Start with 5 to 10mg over 24h	

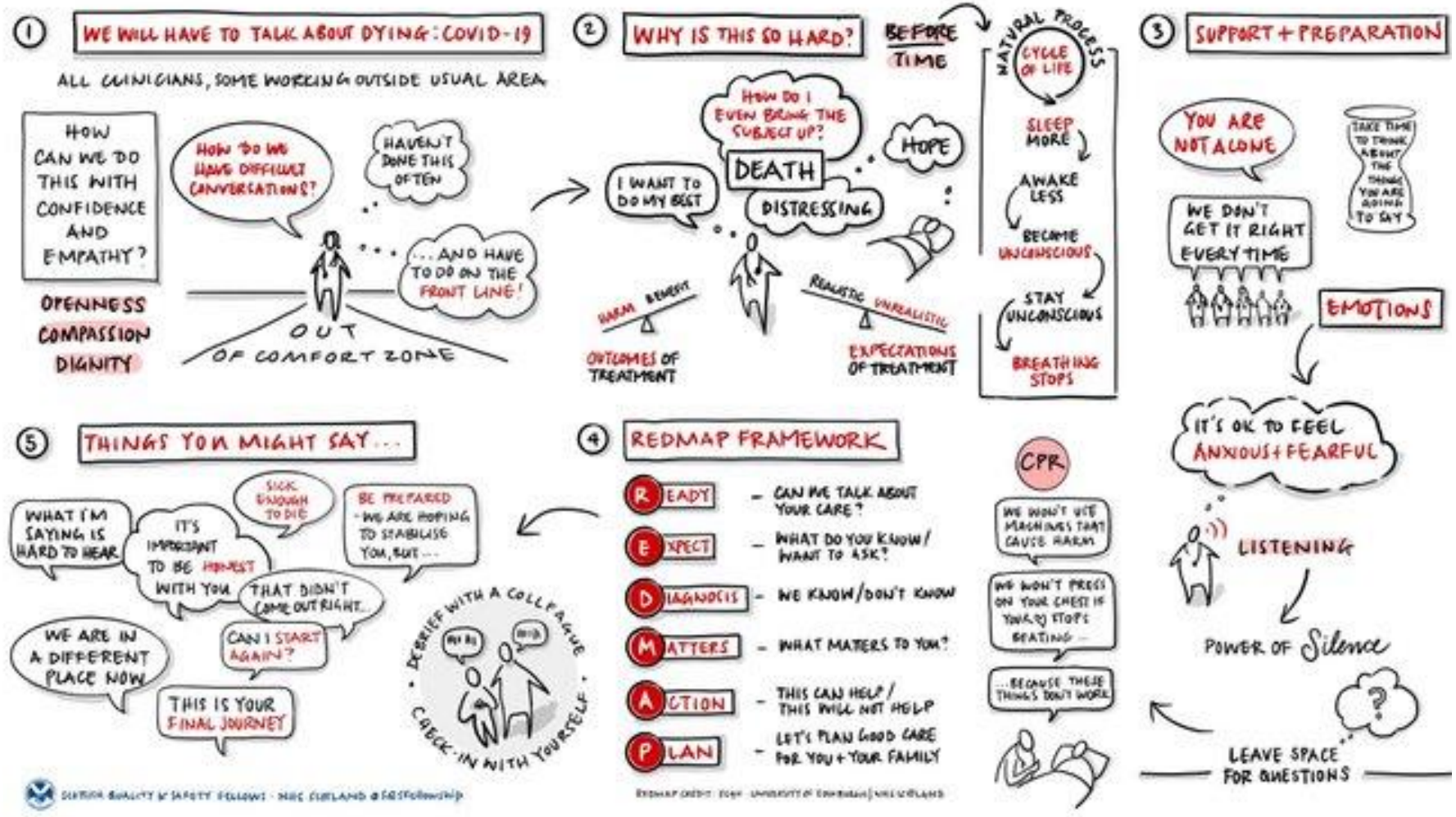
Palliative Care Toolkit

- https://www.gov.scot/publications/coronavirus-covid-19-palliative-care-toolkit/

Syringe drivers and alternatives during COVID

- https://www.palliativecareguidelines.scot.nhs.uk/guidelines/symptom-control/alternatives-to-regular-medication-normally-given-via-a-syringe-pump-when-this-is-not-available.aspx


Communication


1
WE WILL HAVE TO TALK ABOUT DYING: COVID-19
ALL CLINICIANS, SOME WORKING OUTSIDE USUAL AREA
HOW CAN WE DO THIS WITH CONFIDENCE AND EMPATHY?
OPENNESS
COMPASSION
DIGNITY
HOW DO WE HAVE DIFFICULT CONVERSATIONS?
HAVEN'T DONE THIS OFTEN
... AND HAVE TO DO ON THE FRONT LINE!
OUT OF COMFORT ZONE
2
WHY IS THIS SO HARD?
HOW DO I EVEN BRING THE SUBJECT UP?
DEATH
DISTRESSING
I WANT TO DO MY BEST
HOPE
HARM
BENEFIT
OUTCOMES OF TREATMENT
REALISTIC
UNREALISTIC
EXPECTATIONS OF TREATMENT
BEFORE TIME
NATURAL PROCESS
CYCLE OF LIFE
SLEEP MORE
AWAKE LESS
BECAME UNCONSCIOUS
STAY UNCONSCIOUS
BREATHING STOPS
3
SUPPORT + PREPARATION
YOU ARE NOT ALONE
TAKE TIME TO THINK ABOUT THE THINGS YOU ARE GOING TO SAY
WE DON'T GET IT RIGHT EVERY TIME
EMOTIONS
IT'S OK TO FEEL ANXIOUS + FEARFUL
LISTENING
POWER OF Silence
LEAVE SPACE FOR QUESTIONS
4
REDMAP FRAMEWORK
READY - CAN WE TALK ABOUT YOUR CARE?
EXPECT - WHAT DO YOU KNOW / WANT TO ASK?
DIAGNOSIS - WE KNOW/DON'T KNOW
MATTERS - WHAT MATTERS TO YOU?
ACTION - THIS CAN HELP / THIS WILL NOT HELP
PLAN - LET'S PLAN GOOD CARE FOR YOU + YOUR FAMILY
CPR
WE WON'T USE MACHINES THAT CAUSE HARM
WE WON'T PRESS ON YOUR CHEST IF YOUR HEART STOPS BEATING ...
... BECAUSE THESE THINGS DON'T WORK
5
THINGS YOU MIGHT SAY...
WHAT I'M SAYING IS HARD TO HEAR
IT'S IMPORTANT TO BE HONEST WITH YOU
SICK ENOUGH TO DIE
BE PREPARED - WE ARE HOPING TO STABILISE YOU, BUT ...
THAT DIDN'T COME OUT RIGHT...
CAN I START AGAIN?
WE ARE IN A DIFFERENT PLACE NOW
THIS IS YOUR FINAL JOURNEY
DEBRIEF WITH A COLLEAGUE
CHECK-IN WITH YOURSELF

Difficult conversations phone or vc

- Undisturbed
- Check they are able to speak, who is there
- Warning shot
- Check understanding
- What will you do now? Shall we make a plan together? Are there other people you need to tell? Who is there to support you?
- Acknowledge sadness and difficulty of the situation

Video-consultations in Palliative Care

- Increased use for outpatient/ CNS follow up
- Family meetings
- Loss of doorstep conversations
- Still need for FTF assessment- elderly no one to assist with technology/ hard of hearing/ need to see what is going on in home
- Hospices developing virtual services e.g. breathlessness management, counselling, bereavement support

Case History

- 79 metastatic breast cancer
- Fungating breast ca
- Increased pain
- Admitted for symptom control - deteriorated over admission
- AF with reduced saturations, treated for wound infection

- Recognition she was approaching end of life wished home for end of life care
- ‘Nothing you will say will change my mind’
- Complex discharge planning short time frame
- Oxygen (husband smoker)
- Hospital bed, single level living, POC, DNs for syringe driver, catheter and wound care

- Lived with husband, son and daughter in law self isolating ? COVID

Discharge delayed as tested for COVID

- Febrile 24 hrs prior to discharge
- Tested positive COVID 19 (Friday)
- Husband distressed ‘I just want my wife back’
- HSCP, DN, GP informed
- Syringe driver medication, just in case meds. Community Kardex, VOED form
- Discharged home

Disaster!

- Carers refused to visit because of COVID positive status
- Support from DN and Marie Curie Fast Track over weekend
- Family not leaving room
- House crowded with relatives
- Difficulty complying with social distancing
- Pain uncontrolled
- Emergency readmission following the weekend

Re-admitted for end of life care

- Husband unable to visit on readmission
- Staff with her when she died
- Distressing for everyone

Learning

- Early in pandemic-first COVID positive patient for community staff involved
- Less control over family behaviour in community setting (social distancing/ handwashing)
- Moral distress re visiting restrictions
- No PPE available for informal carers at that point

Useful links informal carers

- Scottish Government Website – Coronavirus (COVID-19) unpaid carers providing personal care.
  Information on this website of where to get PPE and who would require it. Social Care PPE Support Centre on 0300 303 3020
- Just in case medication
- Caring for patients in last days of life
- https://helixcentre.com/_content-img/projects/eolc-toolkit/Practical-Care-For-Dying-Person-Toolkit.pdf
- NHSGGC Booklet - What can happen when someone is dying
- NHS Inform – Palliative Care
- NHSGGC Palliative Care Symptom Control

NHSGGC Bereavement Information and Support

References

- Keeley P, Buchanan D, Carolan C, Pivodic L, Tavabie S, Noble S. Symptom burden and clinical profile of COVID-19 deaths: a rapid systematic review and evidence summary. BMJ supportive & palliative care. 2020;28:28.
- Sese D, Makhoul A, Hoeksema L, Shoemaker L. The role of palliative care in COVID-19. Cleve Clin J Med. 2020;29:29.
- Sutherland AE, Stickland J, Wee B. Can video consultations replace face-to-face interviews? Palliative medicine and the Covid-19 pandemic: rapid review. BMJ supportive & palliative care. 2020;26:26.

Questions?

- How can we support end of life care at home for COVID positive patients who do not wish hospital admission
- How do we support those dying following delayed diagnosis or who have not been able to receive treatment e.g. palliative chemotherapy due to COVID
- Bereavement support for families who have not been able to be with loved ones, experience usual rituals around funerals etc