Section Scottish Palliative Care Breathlessness guideline

COMMENTS RECEIVED FROM EXTERNAL REFEREES AND OTHERS

All reviewers submitted declarations of interests which were viewed prior to the addressing of comments.

Open consultation			**Type of response and declared interests**
AS	Anna Sutherland	Palliative Care Consultant, Strathcarron Hospice, Forth Valley	*Individual response.* *Non-financial personal interests* Nausea and Vomiting *Any other interests of relevance* Professional lead for SPCGs
CGD		Yann Maidment, College Lead for Research submitting comments on behalf of the College of General Dentistry	*Group response.* *Nature and purpose of your group or organisation* Professional body comprising of registrant members of the whole dental team. To empower the public and patients to achieve and maintain good oral health through its professional community
ED	Emma Dymond	Consultant in Palliative medicine, Glasgow Royal Infirmary, NHSGG&C	*Individual response.* Nothing declared.
HB	Honor Blackwood	Specialist Nutritional Support Dietitian, NHS Forth Valley	*Individual response.* Nothing declared.
JG	Jennifer Gibson	GP, Lead GP for Palliative Care NHSL, former Palliative Care SAS doctor, NHS Lanarkshire	*Individual response.* Nothing declared.
JM	Jennifer McCraken	Highly Specialist Dietitian, The Royal Marsden	*Individual response.*

			Non-financial personal interests I chair the BDA palliative care subgroup, a special interest subgroup of the BDA Oncology specialist group. Feedback is therefore collated from dietitians with clinical and research experience in palliative care.
LC	Lucy Cogdell	Palliative Medicine Consultant, Roxburghe House, Aberdeen	*Individual response.* Nothing declared.
LH	Lucy Hetherington	Consultant in Palliative Medicine, Beatson, West of Scotland Cancer Centre	*Individual response.* *Non-financial personal interests* I have published a book chapter on substance use and palliative medicine - no financial remuneration
MA	Mairi Armstrong	Macmillan Nurse Facilitator, GGHB	*Individual response.* Nothing declared.
MT	Mandy Trickett	Physiotherapist/Practice Education Lead, NHS Highland	*Individual response.* *Non-financial personal interests* Published work in cancer rehabilitation when worked as a Palliative Care physiotherapist.
RCGP		Marcus Carslaw, Policy and Public Relations Officer submitting comments on behalf of the Royal College of General Practitioners Scotland	*Group response.* *Nature and purpose of your group or organisation* RCGP Scotland is the membership body for general practitioners in Scotland, we exist to promote and maintain the highest standards of patient care.
RP	Rosemary Pengelly	Public Partner, Healthcare Improvement Scotland	*Individual response.* *Any other interests of relevance*

			University of Stirling as an unpaid community researcher.
SD	Siobhan Dobie	Hospital Medical Pharmacist, University Hospital Wishaw, NHS Lanarkshire	*Individual response.* *<u>Financial personal interests</u>* AstraZeneca educational events for COPD

REVIEWER	COMMENT	DEVELOPMENT GROUP RESPONSE	EDITORIAL GROUP RESPONSE
Navigation			
AS	Suggest moving practice points to start of management and using 3 clear bullet points: 1. non-pharm, 2. opioids, 3. benzos as last resort. Then highlight this 3-step approach in the layout of the document with non-pharma, then opioids, then benzos. Suggest moving SVCO/CCF to separate subheadings as these are different scenarios.	We have restructured to: Non pharma Opioids Corticosteroids Benzos We have taken out SVCO and included a link to the palliative emergencies section.	✓
LC	I think the section related to heart failure and furosemide infusions is useful but wonder if it should come in Medication section.	Thank you, the section on furosemide has been moved.	✓
RCGP	We believe it would be beneficial for the guidelines to be reordered so that the management of breathlessness generally is located towards the top of the document, followed by pharmacological and non-pharmacological management, and then rarer causes of shortness of breath such as superior vena cava obstruction and heart failure.	Thank you. We have restructured as you have suggested.	✓
MA	Consider cutting non-pharmacological from its current position to possibly after Medication as the guidance herein probably applies to all	We have restructured to Non-pharma, pharma, heart failure, as suggested in other feedback.	✓

	conditions rather than specifically End Stage Heart Disease	Quick access to all sections will be clearer when the guideline is published in RDS.	
Assessment			
JM	Assessment (p.1) Nutritional assessment included in the multi-professional approach. Non-pharmacological management (p.2) • Small, frequent pattern of meals to avoid pressing on the diaphragm, making it harder to breathe. • Choose nutrient-dense meals. • Limit gas-producing foods (i.e. beans, cabbage, onions, carbonated drinks, fried foods) • Sip fluids throughout the day instead of all at once or instead of drinking with meals. • Chew slowly and sit upright during meals. • Consider oral nutritional supplements if intake has reduced and weight loss has occurred. • Malnutrition screening / monitoring weight • Suggest soft foods which are easier to eat or chop foods into	Thank for your feedback raising very good points. Whilst we are not adding this level of detail into our guideline we wonder if you have a document with these points which could be linked to or a general practice paper. Might be useful to consider in the updating the NHS Inform leaflet. Aimie to contact JM We have added the following to the practice points: Breathlessness can make eating and drinking more challenging. An approach of eating little and often with a high-protein or high-calorie foods can be helpful.	✓ ✓

	small pieces to help with chewing. Encourage nourishing drinks between meals, such as hot chocolate, malted milk drinks or milky coffee made with full cream milk. Nutritional considerations in palliative care highlighted. Responses collated from registered dietitians involved in the BDA Oncology group and Palliative care subgroup.		
Management			
SD	Under management - Acknowledge fear and anxieties and provide supportive care. For example, offer verbal explanation of symptom and written information - could we signpost to relevant written information to support this.	A hyperlink to NHS Inform advice has been added.	✓
MA	Consider adding Management of End Stage COPD and Management of Lymphangitis to list of Management of.....	We have amended oxygen therapy to include COPD/type 2 resp failure.	✓
Superior vena cava obstruction or stridor			
LC	There is another whole section about SVCO under the emergencies section of the guidelines so I think there should be a link to this rather than repeating the management. Perhaps in assessment there could be a bullet point if signs of SVCO refer to SVCO guideline with link.	Agree. We have added a bullet point in assessment and linked to the SVCO section in palliative emergencies.	✓

AS	For Stridor consider adding adrenaline nebulisers (suspect very low-level evidence but used clinically to good effect, dose hard to find as not in BNF and these situations are stressful so would be good suggest this second line, along with sitting the person up, checking sats, clearing any secretions etc.	We have taken out the advice on Stridor and linked to the section in palliative emergencies.	✓
ED	Suggest referencing for the SVCO section the acute oncology society guidance - https://www.ukacuteoncology.co.uk/application/files/9116/9082/2886/UKONS_AO_initial_management_Guidelines_FINAL_VERSION_2023.pdf (page 50 has SVO guidance)	For consistency we prefer to link to our own guidance on SVCO in the palliative emergencies section.	✓
SJ	If stridor or signs of superior vena cava obstruction (SVCO), refer urgently to the appropriate specialist for consideration of, for example, stenting or radiotherapy" This will not always be clinically suitable'; stating it as an instruction lacks person-centred decision making and Realistic Medicine principles.	This section has been removed.	✓

Heart failure (now Use of subcutaneous furosemide)			
ED	For heart failure sections consider adding review local guidance and expertise (there is guidance within our health board created by heart failure MCN)	Thank you for the suggestion but we don't think national guidelines should refer to local guidance. Heading has been changed to "the use of furosemide"	✓ ✓
SJ	Many labs don't do 'U&Es' now - it's C&E - maybe say 'renal function'.	Thank you. This has been changed to 'renal function'.	✓
Non-pharmacological management			
AS	For acupuncture/menthol need to change "should" to "may" be considered if available as evidence base remains low.	Agree. This has been changed to may be considered. Added essential oils and oxygen risk as highlighted by complementary therapy colleagues due to safety concerns.	✓ ✓
LC	I am not sure if there is evidence for menthol cream to help breathlessness? There is evidence for handheld fans so I would write using a handheld fan, opening a window rather than /in between these two separate things.	The reference to the study has been added. We have changed the text from 'should be considered' to 'may be considered' as the evidence is of low quality, but as use of menthol is cheap and accessible it is worth considering. The slash has been removed.	✓ ✓
SD	Could consider nicotine replacement therapies if appropriate?	This has been added: If appropriate, provide smoking cessation advice and consider nicotine replacement. Advise a smoke free environment where possible.	✓
Opioids			
ED	For medicines - reference -Johnson MJ, Currow DC. Opioids for breathlessness:	We have amended the advice for ongoing breathlessness to:	✓

	a narrative review. BMJ Support Palliative Care. 2020 Sep;10(3):287-295. doi: 10.1136/bmjspcare-2020-002314. Epub 2020 Jul 3. PMID: 32620683.- This highlights evidence is best for low dose sustained release morphine (10mg-30mg per day)	If dosing allows, modified release (long-acting) †oral morphine is as effective and often more convenient for patients, plus a 4 hourly equivalent dose of immediate release †oral morphine as required for additional episodes of breathlessness.	
LC	Opioids can reduce breathlessness not just at rest but also on exertion if taken prior to exertion. I would therefore emphasise the importance of timing - taking morphine 15-30mins prior to doing things such as showering that exacerbate breathlessness rather than taking it afterwards. I would not usually advise taking regular immediate release morphine unless breathless all the time and then I would consider a small dose of long acting instead. I would usually initially advise just as required the assess the need for a long acting as well. I think the frequency is inconsistent in the different section of the table about opioids. Why is it 2 hourly initially for as required rather than hourly? With no maximum stated but then under "takes an opioid regularly" a max of 6 as required doses is stated. (Is the maximum of 6 breakthrough doses consistent with other sections of the guidance? Should this be stated in each section as usual maximum or individualised maximum?) Then no maximum stated in frail/elderly section	The first bullet point has been amended to: Can reduce breathlessness at rest on exertion (take 15-30 minutes prior to expected exertion) and in the last days of life. Amended.	✓

	or has ongoing breathlessness section. Ongoing breathlessness section states as required frequency is 4 hourly rather than 2 hourly as above?		
SJ	For medication the dose of opioid depends upon previous tolerance as well. If they are already on 60mg of codeine QDS, 1-2mg morphine SC will be a reduction. 'six doses max.	We have added the following bullet point to the table: If taking a weak opioid consider switching to oral morphine equivalent dosing	✓
Oxygen			
AS	Oxygen – insufficient information here for safe prescribing, suggest separate oxygen section or remove from guidelines, need to state target sats and CO2 retention risk, trip hazard from tubing, other sources of ignition etc	We have added the following bullet point: For Long Term Oxygen Therapy (LTOT) prescription or emergency oxygen treatment in adults in hospital refer to local guidelines.	✓
ED	Oxygen section- appreciate limited data- some info in British thoracic society guidance- given some of info around harm with oxygen in those at risk of type 2 resp failure which includes patients on opioids/benzodiazepines also I wondered if consideration of use for symptomatic patients with SpO2 less than 90% with reference from section K on palliative oxygen use- Guideline for Oxygen use in Healthcare and Emergency Settings - Summary of Recommendations.pdf (on British thoracic society website or via http://bmjopenrespres.bmj.com/ on May 25, 2017	We have added: If there are concerns regarding risk of type 2 respiratory failure, oxygen therapy should only be considered if saturations fall below the patient's target range (usually 88-92%, although may be lower if advised by respiratory specialists).	✓

LC	Oxygen section I would remove the statement important to avoid psychological dependence and instead state that oxygen should only be used if patient is hypoxic. I think it may be helpful to add how to obtain oxygen for a patient at home by contacting oxygen services ?via local hospital.	We have removed the point about psychological dependence and added the following points: Only use if the patient is hypoxic. For Long Term Oxygen Therapy (LTOT) prescription, or emergency oxygen treatment in adults in hospital, refer to local guidelines.	✓
Practice points			
HB	In practice points - Breathlessness can cause increased nutritional requirements and also make eating and drinking harder therefore consideration of implementing a little + often approach to eating of high protein/high energy sources and choose easy to eat/prepare meals/snacks.	We have added the following: Breathlessness can make eating and drinking more challenging. An approach of eating little and often with a high-protein or high-calorie foods can be helpful.	✓
LC	Patient/carer advice section - I am not sure that you can always say that breathlessness on exertion will settle with rest after a few mins. Perhaps may rather than will? I wonder if the last statement in this section would be better as "Anxiety and panic associated with breathlessness can make breathlessness worse so reassurance and other coping strategies may help relieve this distress and therefore reduce breathlessness.	Patient advice has been removed and replaced with a link to the NHS Inform advice under Resources.	✓

Resources			
ED	Resource section really useful- British lung foundation is now called asthma and lung and link redirects to http://www.asthmaandlung.org.uk	Thank you this has been amended to: Asthma and Lung UK: http://www.asthmaandlung.org.uk	✓
LH	SVCO section - the guideline mentions refer urgently to the appropriate specialist - I think it would be helpful to add 'such as Oncology or Respiratory. Then it mentions radiotherapy or stenting - I think it may be worth adding urgent SACT (systemic anti-cancer therapy). As that may be first line treatment in some cancers, particularly lymphoma or small cell lung Ca.	This has been removed and a link to the SVCO advice in palliative emergencies added. This advice will be considered in those sections.	✓
Other			
LH	Update the terminology re 'care in the last days of life' to 'care around dying' as per national recommendation.	In line with Scottish Government advice we have amended the terminology from 'end of life' to 'care around dying' for wider timescales of palliative care and used 'care in the last days of life' for advice pertaining to the period specifically around the last few days.	✓
RP	I note the clear, most helpful, informative and kindly 'patient/carers advice points' section in the breathlessness guideline. The four guidelines seem to have an inconsistency, as getting the patient/carer 'onside' must help also with the easing of the patient and, separately, also the clinical options.	The guidelines are written as practical advice for health and social care professionals. Advice for patients, carers and members of the public is hosted on NHS Inform. The content of the NHS Inform advice on palliative is derived from the guideline In line with our other guidelines and to avoid duplication or inconsistencies in the patient advice, we	✓

	Such inconsistency is a weakness, so please could there be some consistency across the four guidelines, ideally on the ethos as well captured within the breathlessness wording for patients/carers.	have taken out this section and added a link to NHS Inform. Further advice on holistic approaches to care for patients and their families is available in the 'good practice guides' section of the guideline. .	
CGD	The guidelines have been well produced and written. They are sufficiently general that no specific additional guidance appears to be necessary for the special area of general dental and oral health care beyond what appears elsewhere for special situations (e.g. oncology care). An old (Galen, 2nd century A.D) piece of guidance that ""the extraction of teeth should not be undertaken - unless there is no alternative"", still holds true - even more so in palliative care.	Thank you for your kind words regarding the guidelines. We appreciate your recognition of their clarity and comprehensiveness. We agree that the general principles outlined in the guidelines should be sufficient for most dental and oral healthcare situations, including palliative care.	✓
ED	Well laid out and easy to read with good information.	Thank you for your positive feedback.	✓
JG	This is excellent and easy to use, no changes to suggest	Thank you for your valuable feedback	✓
LH	There is some inconsistency re use of full stops in the guideline.	Thank you for bringing this inconsistency to our attention. We will proofread the guideline prior to publication.	✓
MT	All appears relevant and up to date. Keen to see importance of physical activity and regular postural/positional changes.	Thank you for your feedback. We agree that physical activity and regular postural/positional changes are important for overall health and well-being, especially for individuals with limited mobility.	✓

		We include the point: Advise to manage and try to maintain activity levels	
RCGP	RCGP Scotland welcomes the opportunity to provide feedback on updates to Scottish Palliative Care Guidelines. As the membership body for general practitioners in Scotland, we exist to promote and maintain the highest standards of patient care. GPs play an important role in the management of patients undergoing palliative care, particularly if the patient has elected to be cared for in community settings. RCGP Scotland broadly welcomes the updated guidelines regarding breathlessness. We note that the management section states the principles of caring for a patient with shortness of breath without signposting that more detailed advice is found further down the document. If a doctor were to be referencing the guidelines while pressured for time this may not be immediately evident, and steps should be taken to ensure that management options are clearly signposted.	Thank you for your comments, this will be clearer on the RDS site.	✓

	We welcome the specific focus on the management of shortness of breath related to end-stage heart failure. Furthermore, we note that the pharmacological management options are well evidenced, and this information is presented clearly. The College welcomes the use of practice points as they are good way to summarise the information contained within the document. It may be beneficial to have the practice points at the beginning of the document labelled as 'take home messages'. This would allow for staff working under time constraints to quickly access important information without having to always scan through the whole document. The Scottish Palliative Care Guidelines are a useful resource for GPs treating palliative care patients and the updated guidelines offer an improvement on previous versions. The College feels it would be useful for the guidelines to be made available via an app to allow ease of access to the information via mobile devices on home visits. This would be of particular benefit to doctors working in remote and rural areas where internet connectivity may be patchy or limited.	The updated guideline will be published on the Right Decision Service alongside the rest of the Scottish Palliative Care guideline. Users can download the app version for use without internet access.	✓