StChristopher's

Pain and dementia: assessment/management

Dr. Julie Kinley
Nurse Consultant for Care Homes
Care Home Project Team
St Christopher's
j.kinley@stchristophers.org.uk

Overview of presentation

- Review key concepts about pain and the experience of pain for residents with dementia
- Understand the options for assessing pain in residents with dementia
- Complete a validated pain assessment tool
- Present a guide for pain management

StChristopher's

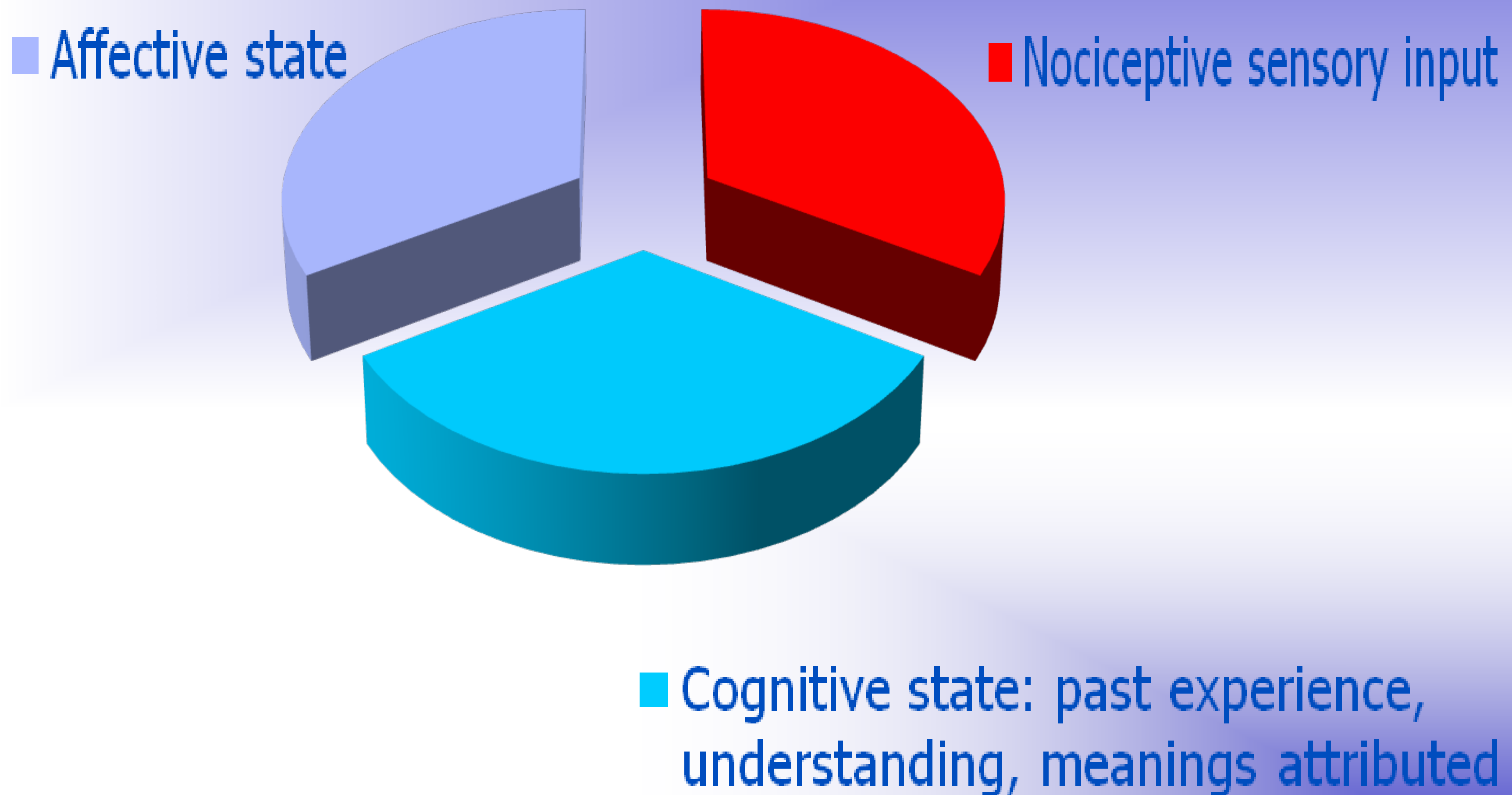
Definition of Pain

'Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage. Each individual learns the application of the word through experiences relating to injury in early life. It is unquestionably a sensation in a part or parts of the body, but it is always unpleasant and therefore an emotional experience'

(International Association for the study of pain 1986)

StChristopher's

Components of the pain experience



StChristopher's

Do we need to pay attention?

A systematic review: prevalence of pain 14-63%

Moens et al *JPSM 2014*

Another review suggested 32-80%

Corbett et al *Br Med Bull* 2014

Commonest symptom in the last week of life in advanced dementia: 52%

Hendricks et al *JPSM* 2014

StChristopher's

Common causes of pain in dementia

1. **Acute pain**

e.g. Toothache
cellulitis
DVT

2. **Chronic pain – wear+tear+frailty**

e.g. arthritis
pressure ulcers
spasticity
contractures

3. **Incident pain**, usually precipitated by dressing changes or movement in bedbound patients
4. **Neuropathic pain**

StChristopher's

Current thinking

It is likely that people with Alzheimer's feel more pain but can express it less

StChristopher's

Why does pain affect behaviour in dementia?

No past /no future

The present is everything

Unable to split attention

In advanced dementia, pain occupies the whole of consciousness – it becomes their whole world

"Triangulation" of pain assessments

Self-reporting

Examination

Observation

Therapeutic trial

StChristopher's

City of hope pain and palliative care resource centre

State of the Art Review of Tools for Assessment of Pain in Non-verbal Older Adults

http://prc.coh.org/pain-noa.htm

StChristopher's

Pain instruments for non-verbal patients

Doloplus-2

DOLOPLUS-2 SCALE BEHAVIOURAL PAIN ASSESSMENT IN THE ELDERLY

NAME : Christian Name : Unit :

Behavioural Records

Item	Description	DATES			
SOMATIC REACTIONS					
1• Somatic complaints	• no complaints	0	0	0	0
	• complaints expressed upon inquiry only	1	1	1	1
	• occasional involuntary complaints	2	2	2	2
	• continuous involuntary complaints	3	3	3	3
2• Protective body postures adopted at rest	• no protective body posture	0	0	0	0
	• the patient occasionally avoids certain positions	1	1	1	1
	• protective postures continuously and effectively sought	2	2	2	2
	• protective postures continuously sought, without success	3	3	3	3
3• Protection of sore areas	• no protective action taken	0	0	0	0
	• protective actions attempted without interfering against any investigation or nursing	1	1	1	1
	• protective actions against any investigation or nursing	2	2	2	2
	• protective actions taken at rest, even when not approached	3	3	3	3
4• Expression	• usual expression	0	0	0	0
	• expression showing pain when approached	1	1	1	1
	• expression showing pain even without being approached	2	2	2	2
	• permanent and unusually blank look (voiceless, staring, looking blank)	3	3	3	3
5• Sleep pattern	• normal sleep	0	0	0	0
	• difficult to go to sleep	1	1	1	1
	• frequent waking (restlessness)	2	2	2	2
	• insomnia affecting waking times	3	3	3	3
PSYCHOMOTOR REACTIONS					
6• washing &/or dressing	• usual abilities unaffected	0	0	0	0
	• usual abilities slightly affected (careful but thorough)	1	1	1	1
	• usual abilities highly impaired, washing &/or dressing is laborious and incomplete	2	2	2	2
	• washing &/or dressing rendered impossible as the patient resists any attempt	3	3	3	3
7• Mobility	• usual abilities & activities remain unaffected	0	0	0	0
	• usual activities are reduced (the patient avoids certain movements and reduces his/her walking distance)	1	1	1	1
	• usual activities and abilities reduced (even with help, the patient cuts down on his/her movements)	2	2	2	2
	• any movement is impossible, the patient resists all persuasion	3	3	3	3
PSYCHOSOCIAL REACTIONS					
8• Communication	• unchanged	0	0	0	0
	• heightened (the patient demands attention in an unusual manner)	1	1	1	1
	• lessened (the patient cuts him/herself off)	2	2	2	2
	• absence or refusal of any form of communication	3	3	3	3
9• Social life	• participates normally in every activity (meals, entertainment, therapy workshop)	0	0	0	0
	• participates in activities when asked to do so only	1	1	1	1
	• sometimes refuses to participate in any activity	2	2	2	2
	• refuses to participate in anything	3	3	3	3
10• Problems of behaviour	• normal behaviour	0	0	0	0
	• problems of repetitive reactive behaviour	1	1	1	1
	• problems of permanent reactive behaviour	2	2	2	2
	• permanent behaviour problems (without any external stimulus)	3	3	3	3
	SCORE				

COPYRIGHT

Pain assessment for people with dementia

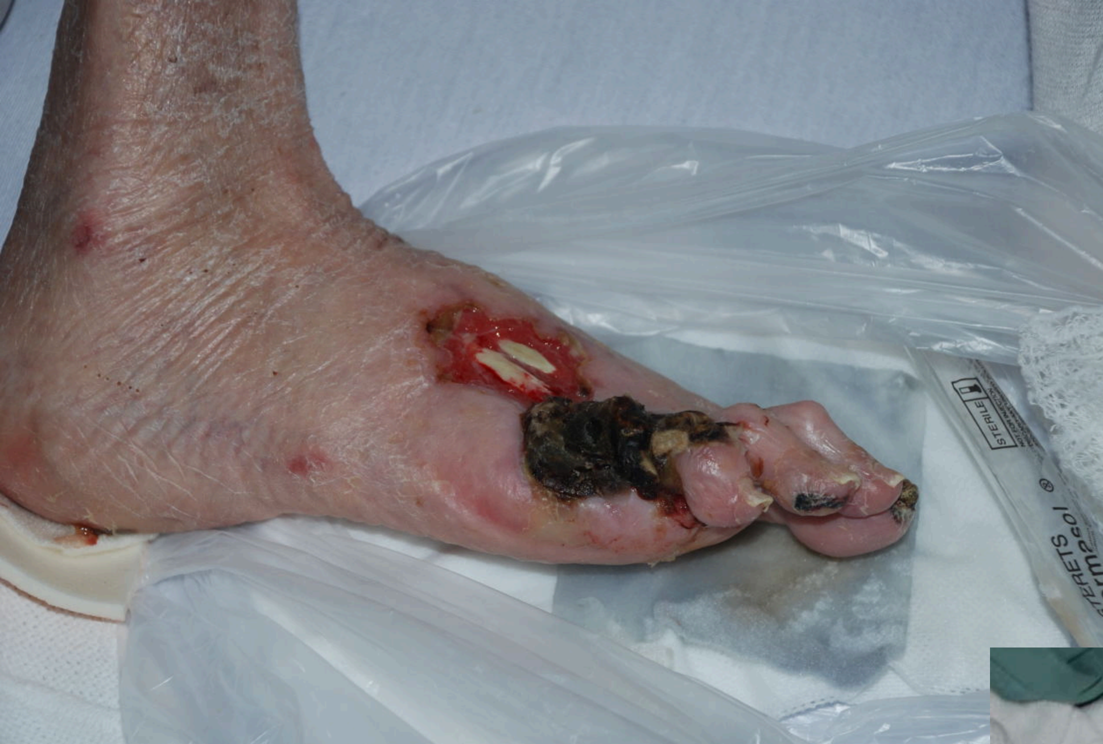
- Film and case studies

St Christopher's

Difficulties with behavioural scales

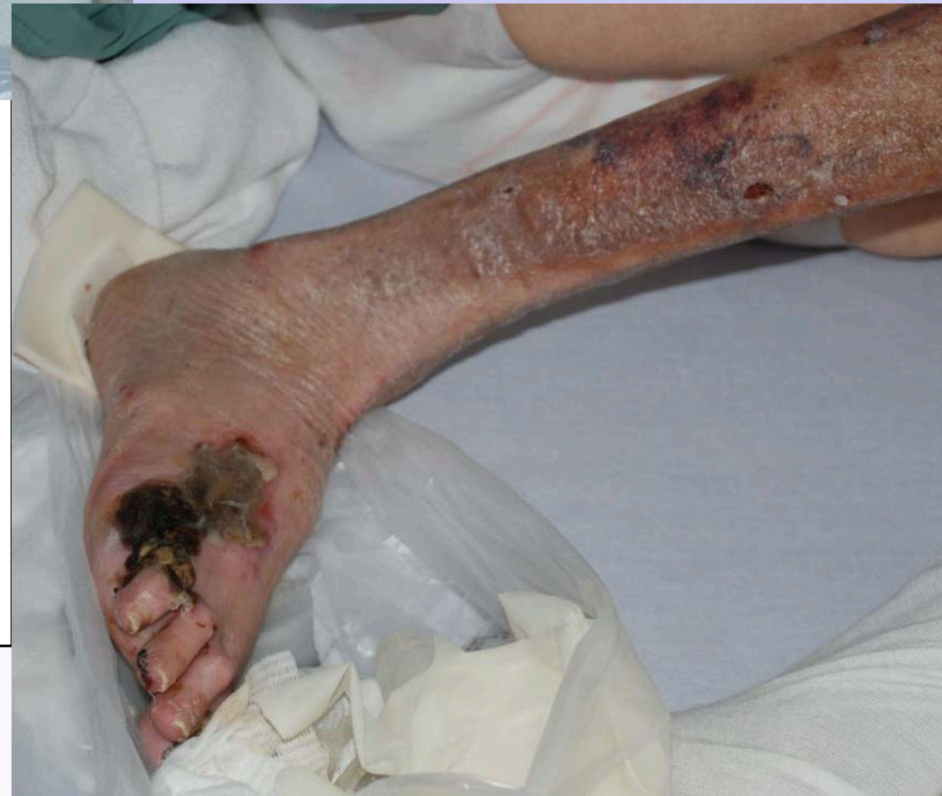
- No behaviours are unique to pain
- Behaviours are unique to the individual
- How accurately do carers notice behaviours?

NOT EASY!



Out of fear of side-effects from painkillers, this patient was only prescribed paracetamol as required by the GP

With a small dose of morphine regularly and before changes in dressing or position, she became communicative, happy, and started to eat again



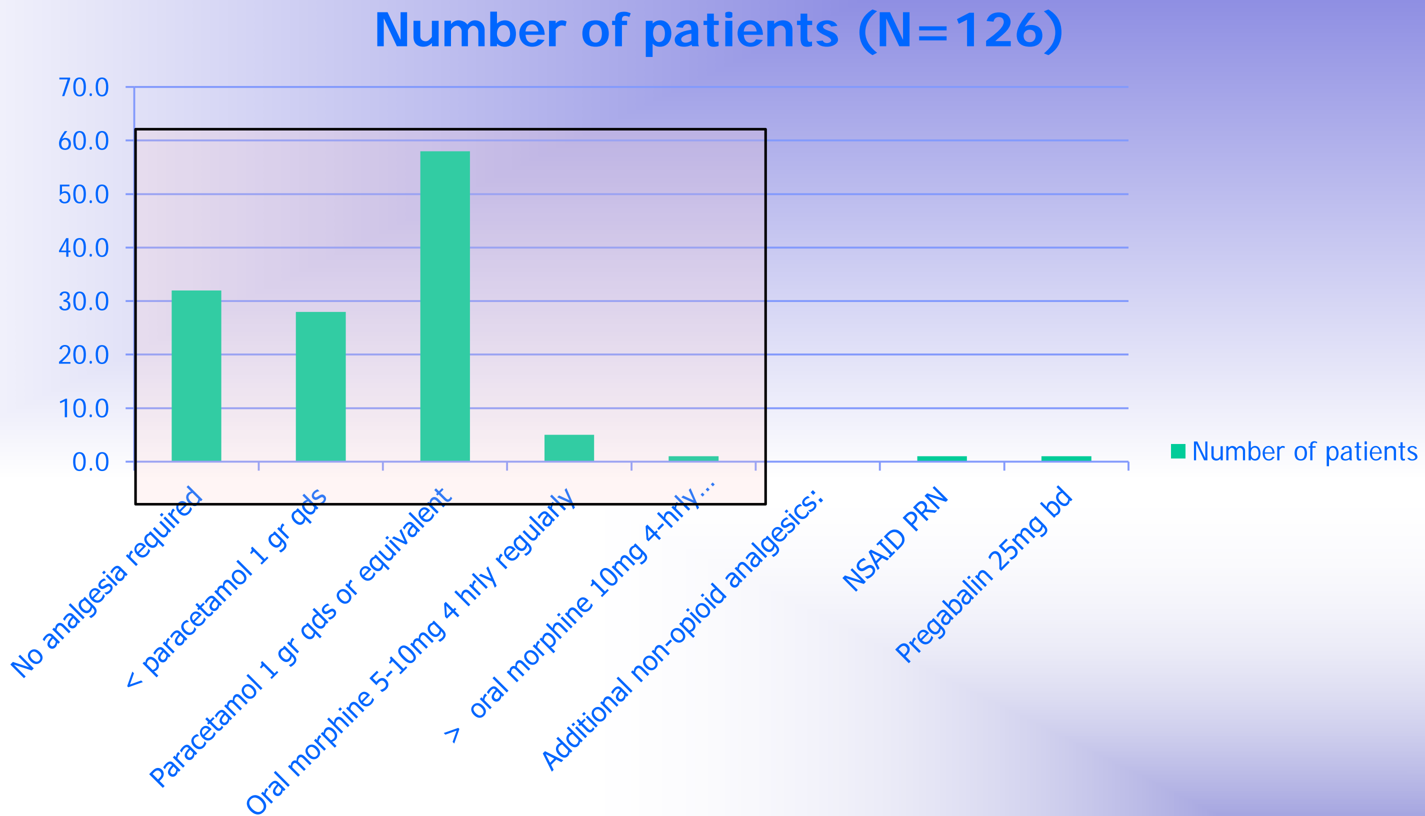
StChristopher's

Why is pain so badly managed?

St Christopher's

An exploration of the palliative care needs of people with dementia & their families – St Christopher's Croydon Dementia Project

(Pace & Scott 2010)



StChristopher's

Analgesic Ladder

Strong opioid
+ non opioid
±adjuvants
Step 3

Weak opioid
+non opioid
±adjuvant
Step 2

Non opioid
±adjuvant
Step 1

StChristopher's

Threshold raised

Sleep
Relief of symptoms
Sympathy
Understanding
Companionship
Divisional Activity
Anxiolytics
Anti Depressants

Management of pain in the last days of life for frail older residents in care homes

Research

A baseline review of medication provided to older people in nursing care homes in the last month of life

Julie Kinley, Jo Hockley

Abstract

Aim: Increasing numbers of older people are dying in the nursing care home setting. Little is known about the medication needs of the very old and frail in the last weeks of life and how they might differ from a model of care developed for people dying from cancer. ***Method:*** A baseline review of medication in the last month of life was undertaken to try and establish current practice of prescribing for this population. The notes of 48 deceased residents in seven nursing care homes were examined, alongside a questionnaire sent to 67 trained nurses. ***Results:*** Subcutaneous prescribing only occurred where specialist palliative care teams had been involved with the residents' care. Syringe drivers were used in 23% of cases; however, only three residents required a syringe driver for more than a day and a half. Nurses' confidence and competence in setting up syringe drivers was varied. ***Conclusions:*** The use of syringe drivers may not be the most appropriate way of managing symptoms during the dying phase in very frail and old people.

Key words: Nursing care homes ● End-of-life care ● Audit ● Syringe drivers ● Medication ● Older people

Sixteen percent of UK deaths now occur in care homes (Tebbit, 2008), with the majority of people dying in a nursing care home (NCH). This highlights the need to ensure that the staff working in NCHs have, or are assisted to gain, the skills to meet their residents' end-of-life care needs. The concept of a palliative care approach in the care of people with advanced, progressive and incurable disease is new for many staff in NCHs where there is still a 'striving to keep [people] alive culture' (Hockley, 2006). The poor recruitment and retention of staff, particularly in some NCHs, also mitigates against the preservation of new knowledge and approaches. Few NCHs have direct contact with local specialist palliative care services (perhaps because less than 10% of residents in NCHs have a diagnosed cancer). The majority of residents in care homes also may not meet referral criteria for specialist palliative care involvement.

Residents within NCHs are recognized as having symptom control problems. A chart review of 185 residents in a long-term care facility in the United States (US) revealed that in the last 48-hours of life, 53% of residents had three or more symptoms, with dyspnoea being the most prevalent symptom (Hall et al, 2002). Even though this study was carried out in the US, the sample appears representative, with only 14% of residents having a cancer diagnosis. The *End of Life Care Strategy* (Department of Health (DH), 2008) encourages the implementation of various end-of-life care tools: the Preferred Priority of Care; the Gold Standards Framework in Care Homes (GSFCH); and, the Liverpool Care Pathway for the Dying. By introducing such tools it is hoped that staff will become more confident and competent in managing their residents' end-of-life care.

Reasons for undertaking the baseline review

St Christopher's Hospice became a regional training centre for GSFCH in September 2008 following the establishment of a specific care home project team at the hospice. The aim of the team is to empower staff in local NCHs to meet the generalist palliative care needs of their residents and families. Although all members of the team come from a specialist palliative care background, a specific intention of the team is to learn with care home staff how to manage the dying process of frail older people.

It is now well established that NCHs may require a different model when providing end-of-life care rather than imposing a specialist palliative care model that has been established for cancer patients and their families (Froggatt, 2001; Hockley, 2006). Syringe drivers have traditionally been a tool of specialist palliative care to manage complex symptoms in the last days of life. However, the use of syringe drivers often presents safety and/or management concerns in non-specialist units (Dunne et al, 2000; McCormack et al, 2001) and by non-specialist nurses (McCormack et al, 2001; Hayes et al, 2005). As a result, use of syringe drivers within NCHs may be neither necessary nor appropriate.

Julie Kinley is Research Practice Nurse, and Jo Hockley is Nurse Consultant for Care Homes, St Christopher's Hospice, London

Correspondence to: ***Julie Kinley*** j.kinley@stchristophers.org.uk

Guidance

'Anticipatory medication' guidance

This guidance is for symptom control in the last days of life for very frail older people dying in care homes who do not have specialist palliative care needs. Frail older people are defined as 'aged over 75 years with the presence of multiple chronic diseases' (Kinley et al (2013) Anticipatory end of life care medication for the symptoms of terminal restlessness, pain and excessive secretions in frail older people in care homes. *End of Life Journal* Vol. 3, No. 3, pages 1-6)

PAIN		
Dying itself is not painful but some older people who have required regular oral analgesia will require a substitute when they can no longer swallow. All residents should have access to analgesia.		
Drugs to choose from	**Dose**	**Frequency**
Paracetamol suppositories **or**	0.5 to 1g	prn 4 to 6hrly (maximum 4g/24hrs)
s/c Morphine (see overleaf for equivalents)	1 to 5mg	prn (4 to 6hrly)*
When a resident already has a transdermal analgesic patch (buprenorphine or fentanyl) these must be continued. 'prn' analgesia should also be available	See 'Guide to dose equivalents for morphine' on next page (patches take up to 24hrs to become fully effective)	
TERMINAL RESTLESSNESS		
If a resident has been on long-term anti-psychotics, anxiolytics or anti-epileptics and is now unable to swallow seek specialist advice.		
Drugs to choose from	**Dose**	**Frequency**
Diazepam rectal solution e.g. Stesolid **or**	5 to 10mg	prn
s/c Midazolam **or**	1 to 2 to 5mg	prn (2 to 4hrly)
s/c Haloperidol**	0.5mg	prn
SECRETIONS		
To prevent excessive tracheal secretions. If the 'rattly' chest is due to end-stage pneumonia an anticholinergic is unlikely to work, consider repositioning the resident (this may be in the recumbent position).		
Drugs to choose from	**Dose**	**Frequency**
s/c Glycopyrronium	200 micrograms	prn (4 to 6hrly)
s/c Hyoscine Butylbromide (Buscopan)	10 to 20mg	prn (4 to 6hrly)
OTHER SYMPTOMS		
NAUSEA AND VOMITING		
Drugs to choose from	**Dose**	**Frequency**
s/c Haloperidol** **or**	0.5mg	prn
i/m Cyclizine (can be painful) **or**	25 to 50mg	prn (8hrly)
Domperidone suppositories	10mg	prn
BREATHLESSNESS		
Drug	**Dose**	**Frequency**
s/c Morphine	1mg	prn (4 to 6hrly)

Caution is required when prescribing as many residents will have renal impairment
* 'prn' medications can be repeated once within an hour if the first dose was not effective
** Avoid completely in residents with Lewy Body Dementia and/or Parkinson's

StChristopher's

Points to remember

- Good pain assessment means better pain control
- Listen to and observe your residents. Don't make assumptions and pre judge
- Remember residents may have more than one pain, some will have several. They need treating individually-the nature and cause of each pain will be different
- Remember to look at the whole resident, be alert to other factors that affect the perception of pain
- Reassess regularly