

Optimising quality of life in pancreatic cancer

10th September 2025 9:00 – 11:00am Via Zoom Webinar



Welcome and introduction

Nicci Murphy Clinical Lead and Pancreatic Cancer Specialist Nurse, Pancreatic Cancer UK



Agenda

09.00 – 09.05	Welcome – Nicci Murphy, Clinical Lead and Pancreatic Cancer Specialist Nurse, Pancreatic Cancer UK
09.05 – 09.20	Introducing quality of life and key themes – Lynne McCallum, Pancreatic Cancer Specialist Nurse, Pancreatic Cancer UK
09.20 – 10.30	Case study and panel session – chaired by Nicci Murphy, Clinical Lead Specialist Nurse, Pancreatic Cancer UK • Dr Robin Muir • Neil Bibby • Melanie Allen • Dr Ruth Corbally • Gemma Kindness
10.30 – 10.50	Q&A – with our panellists, chaired by Nicci Murphy

10.50 – 11.00

Close



Quality of Life in Pancreatic Cancer: A Refresher

- Defining Quality of Life (QoL)
- Core Pillars of QoL
- QoL Considerations in PDAC
- Approaches to Assessing QoL



"person's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."





What Quality of Life Means for Patients

- Active involvement in their own care
- Reduced anxiety and improved mood
- Better response to treatment
- Faster and more effective recovery
- Ability to focus on what matters most
- Greater sense of control and independence
- Enhanced capacity to achieve personal goals

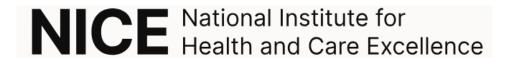
Why Quality of Life Matters in PDAC



- Cancer impacts QoL across physical, emotional, and social domains
- Challenges are often more pronounced in pancreatic cancer
- PDAC typically presents late with high symptom burden
- Low mood is more prevalent in PDAC than other cancers
- Severe symptoms often persist to end of life, contributing to poor QoL







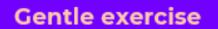
Pancreatic cancer in adults: diagnosis and management

NICE guideline | NG85 | Published: 07 February 2018

- People should have access to psychological support throughout their care pathway
- Support should be tailored to individual needs
- There should be assessment of the psychological effects of:
 - Fatigue
 - Pain
 - GI symptoms including nutrition
 - Nutrition
 - Anxiety
 - Depression









Emotional well-being



Diet and digestion



Treat any symptoms







- A key component of personalised, holistic care
- Helps us understand the impact of PDAC on everyone's life
- Supports timely, person-centred palliative and supportive care
- Offers insight into the lived experience of illness over time

The challenges



- Defining and measuring quality of life is complex
- Multiple assessment tools exist selecting the most appropriate can be challenging
- Time limitations in clinical practice
- Constraints of the clinic environment
- Resource and staff capacity considerations
- Determining responsibility for conducting assessments

Using the right tool for the job!



Quality of life measurement tools need to be:

- Easy to complete
- Not too long
- Can be used and repeated at relevant times
- Meaningful to the patient
- Actionable
- Not only focussed on treatment and/or symptom metrics
- Can be used to develop care plans based on the priorities of the individual
- It enables the individual to make informed decisions

What tools do you use in your practice?



What tools did I use in practice?

- EORTC QLQ-C30
- EORTC QLQ PAN26
- Holistic Needs Assessment (HNA)
- Eastern Cooperative Oncology Group Performance Status (ECOG PS)

Examples

1

2

3

4

5

Restricted in physically strenuous activity but ambulatory and able to

office work

50% of waking hours

Completely disabled; cannot carry on any selfcare; totally confined to

bed or chair

Dead





EORTC QLQ-C30 (version 3)

We are interested in som number that best applie remain strictly confident



EORTC QLQ - PAN26

carry out work of a light or sedentary nature, e.g., light house work, **Specimen-PAN26** Ambulatory and capable of all selfcare but unable to carry out any work activities; up and about more than 50% of waking hours Capable of only limited selfcare; confined to bed or chair more than

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

Specimen-QLQ-C30.pdf

Macmillan HNA

ECOG performance status

The ECOG Performance Status Scale was developed by the Eastern Cooperative Oncology Group (ECOG), now the ECOG-ACRIN Cancer Research Group, and published in 1982. To learn more, visit ecoq-acrin.org/scale.

Concerns Checklist -		Physical concerns			Sex, intimacy or fertility		Loneliness or isolation
identifying your concerns			Breathing difficulties		Other medical conditions		Sadness or depression
			Passing urine	Practical concerns			Hopelessness
Patient's name or label			Constipation		Taking care of others.		Guilt
Tatient s name of laber			Diarrhoea		Work or education		Worry, fear, or anxiety.
			Eating, appetite or taste		Money or finance		Independence
			Indigestion		Travel	Family or relationship concerns	
			Swallowing		Housing		Partner
			Cough		Transport or parking		Children
Key worker:			Sore or dry mouth or ulcers		Talking or being understood		Other relatives or friends
			Nausea or vomiting		Laundry or housework		Person who looks after me
Date:			Tired, exhausted or fatigued		Grocery shopping		Person who I look after
			Swelling		Washing and dressing		tual concerns
Contact number:			High temperature or fever		Preparing meals or drinks		Faith or spirituality
This self-assessment is optional; however, it will help us understand the concerns and feelings you have. It will also help us identify any information and support you may need.			Moving around (walking)		Pets		Meaning or purpose of life
			Tingling in hands or feet		Difficulty making plans.		Feeling at odds with my culture, beliefs or values
			Pain or discomfort		Smoking cessation	Information or support	
			Hot flushes or sweating		Problems with alcohol or drugs		Exercise and activity
If any of the problems listed have caused you concern recently and you wish to discuss them with a key worker, please score the concern from			Dry, itchy, or sore skin		My medication		Diet and nutrition
			Changes in weight		Emotional concerns		Complementary therapies
1 to 10, with 10 being the highest. Leave the box blank if it doesn't apply to you, or you don't want			Wound care		Uncertainty		Planning for my future priorities
todiscuss it now.			Memory or concentration		Loss of interest in activities		Making a will or legal advice
Key worker to complete			Sight or hearing		Unable to express feelings		Health and wellbeing
			Speech or voice problems		Thinking about the future		Patient or care support group
			My appearance		Regret about the past		Managing my symptoms
	Copy given to patient.		Sleep problems		Anger or frustration		Sun protection
	Copy to be sent to GP						
☐ I have questions about my diagnosis, treatment, or effects.							
				g			

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Final Reflections on Quality of Life



- It is unique to the individual
- Consider in every clinical encounter
- Central to personalised, holistic care
- Symptom management reduces distress and enhances QoL
- Empowers patients and their loved ones
- Communication is our most valuable tool
- Requires a coordinated MDT approach

#PCUKStudyDay



Case Study 1

Barbara, 67, presented with onset of jaundice. Imaging showed an operable mass on the head of pancreas and referred to surgery.

Barbara lives alone but has good family and friend support locally. Surgery planned for 3 weeks' time.

Recent ERCP for bile duct stent, bilirubin levels decreasing and symptoms improving. No signs of infection, eating and drinking well.

ECOG Performance Status – 1

Current issues:

- Recent unexplained weight loss
- Pale stools.
- Some discomfort to abdomen, worse as day progresses.

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Case Study 2

Sarah, 71, diagnosed with inoperable head of pancreas cancer, with known liver metastases. Has been offered Gemcitabine Abraxane chemotherapy and is due to start in 4 weeks' time.

Lack of social support. Sarah is the main carer for husband with dementia.

ECOG Performance Status - 2

Current issues:

- Emotional distress, fears for the future.
- Anorexia and ongoing weight loss, ++.
- Elevated Hba1c, abdominal pain, insomnia.

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Case Study 3

Bob, 71, found to have metastatic disease within 12 months of Whipple's surgery and adjuvant FOLFIRINOX chemotherapy.

Considers treatment options but has made the decision (with support from family) to focus on quality of life so declines chemotherapy.

Bob's son is getting married in 2 months' time and his focus is being able to attend the wedding.

ECOG Performance Status – 2

Current issues:

- Pain
- Ongoing diarrhoea since surgery
- Reduced mobility
- Chemotherapy induced peripheral neuropathy



Key takeaway messages

- Check that any patient with pancreatic cancer is being prescribed PERT. Don't be afraid to trial higher doses if needed. If your patients need further support with taking PERT, the Pancreatic Cancer UK Support Line is available.
- Prioritise proactive care and communication, early interventions and support, rather than waiting for problems to arise.
- Good care is built upon professionals working across different domains and in a multidisciplinary manner, i.e. considering treatment decisions in terms of what the person values.
- **Be aware of patients' additional challenges**, respond to these and consider how we can support patients to be involved in their own care.
- Find out what services are available in your area that can offer help and support for your patients and families. There are often council and charity led resources that we can tap into in addition to our NHS resources.
- Don't hesitate to discuss physical activity. You don't need to be an expert in it encouraging
 movement is generally safe and offers significant health benefits. Even small increases in activity can
 make a meaningful difference