

## **Video Transcript:**

### **Using the Integrated Palliative care Outcome Scale (IPOS) in the dying Phase of Illness**

We use the Integrated Palliative care Outcome scale (IPOS) across all of the palliative Phases of Illness, including stable, unstable, and deteriorating, during clinical assessments.

In the dying Phase it can be particularly challenging to use IPOS. This is partly because people are very unwell and are often (but not always) semi-conscious, or unconscious in the last few days of their lives.

Completion of the patient recorded version of IPOS is often impossible because people are too ill, but it is possible to use the staff version of the IPOS measure. This needs to be done through skilled observation, spending time with the patient, watching for evidence of symptoms, and listening to family when they are present.

### **Why should I use IPOS in the dying Phase?**

Remember that the IPOS measure asks about symptoms or concerns over the previous 3 days for inpatient settings, or previous 7 days in the Community setting. Using IPOS in the dying Phase can help assess whether the last 3 or 7 days of life were peaceful, free of pain, free of respiratory problems, free of restlessness.

IPOS also looks at the levels of anxiety felt by the patient's family. It is important to measure any changes in the staff-reported version of IPOS at this point because otherwise how do we know if our delivery of care in the dying phase is working well or not? How can we assess this if we don't use a standardized method to capture patient symptoms and the related provision of our care in a consistent way?

### **Capturing thoughts and assessments**

The staff version of IPOS asks us to make our best clinical judgement about how a patient may be affected by symptoms and concerns.

When asking yourself the question “how have things been in the last 3 days for this patient”? Listen to the views of your team and reflect on how things have been for the patient and their family, and how you have made a difference.

As you work your way through the IPOS assessment during the dying Phase of Illness, consider first the patient’s main problems or concerns. Question 1 is still an important question at this stage and is particularly helpful for the next professional to see what the patient’s main problems are. These problems or concerns are derived from your judgement, information from the patient’s family, and from your colleagues and the supporting team.

### **Working through the IPOS staff-completed measure in the dying Phase of Illness**

In relation to the main symptom questions on the IPOS form, you may then like to consider the following in Question 2:

Pain – using different signs, so, if the patient isn’t speaking these may include facial expressions or grimacing, or clearly wincing, being resistant to movement, or stiffness. You can judge how moderate, severe, or overwhelming pain might be by taking into account how the patient is affected by it.

Shortness of breath – in the dying Phase, this is assessed slightly differently by respiratory rate and noisy breathing, and whether you think that your patient is bothered by these symptoms or any associated discomfort. You can assess whether there is distress around breathing. Is it laboured? Again, this may be considered slight, moderate, severe, or overwhelming.

Symptoms of sore or dry mouth, can be readily assessed by direct inspection, and also constipation would be clinically assessed in the dying Phase – note whether or not these symptoms are affecting the patient in a slight, moderate, severe or overwhelming way.

### **When I “cannot assess”**

Some of the IPOS items such as weakness or lack of energy, nausea, poor appetite, cannot usually be assessed in the dying Phase, and so usually the response here on the staff-reported form is “cannot assess”.

Similarly, drowsiness and poor mobility are also subjective responses in the sense that only the patient themselves can let us know how they are affected. We would therefore score as “cannot assess”.

Vomiting is usually witnessed, although not that common in the dying Phase of Illness, and you will need to assess in the usual way by asking family and colleagues, then indicating your response on the form – not at all, slightly, moderately, severely etc.

### **How do I assess family anxiety?**

Neither the anxiety question (Question 3) or feeling depressed question (Question 5) can be assessed without really being able to communicate and listen to your patient.

However, family anxiety (Question 4) can often be assessed if you see the patient’s family or they are present at assessment. Sometimes when we haven’t met the family we have to indicate ‘cannot assess’ on the IPOS form.

However, we should be trying to make an estimate of what is happening for them, and if they are not present, telephoning them to ask how they are. This may then be possible to score, making your best judgement.

### **“At peace”**

The ‘at peace’ question on the IPOS form (Question 6) is very useful in the dying Phase of Illness. You may not know the reason why your patient is not at peace – it may be due to a physical, psychological, or spiritual reason, but you can assess whether they seem to be peaceful or not on the basis of their restlessness or agitation.

The two items on ‘sharing feelings’ and ‘information needs’ (Questions 7 & 8) cannot usually be assessed unless the patient is conscious and able to talk, and should therefore also be completed as “cannot assess” if the patient is unable to communicate.

Your assessment may be an indicator of underlying problems which have not already been captured in IPOS, and which may in turn highlight any problems that need your further attention and care.

## **Practical problems in the dying Phase of Illness**

You may encounter some practical problems when caring for patients in the dying phase, such as personal needs, availability of equipment, dealing with finances, caring for pets etc. especially in community settings. Any practical problems should be assessed and scored on the IPOS form (Question 9) in the usual way.

## **Scoring IPOS in the dying Phase**

Using IPOS can help staff to recognise whether somebody had their symptoms addressed and resolved in the last few days of life (or not). This in turn, can support the team in the delivery of care to patient and family.

When completing the IPOS form in the Dying Phase it is *not possible* to calculate a “total” or “sub-scale” score, as some of the questions cannot be answered at this point in time.

The first open question (Question 1) is not scored, and “other symptoms” item at the end of Question 02 is not scored.

However, you can score the individual IPOS items as shown here, and calculate the change in these scores over time.

## **References**

IPOS is a valid and reliable assessment and outcome measure for use with people with advanced illness, both in its patient self-report and staff proxy-report versions.  
<https://journals.sagepub.com/doi/epub/10.1177/0269216319854264>

IPOS is suitable for assessing and monitoring the symptoms and concerns of those with advanced illness; monitoring change over time, determining the impact of healthcare interventions, and demonstrating quality of care.

Palliative ‘Phase of Illness’ is used in advanced illness to describe the distinct stages of an individual’s illness according to the care needs of the individual and the family, and the suitability of the current care plan to address these needs.  
<https://journals.sagepub.com/doi/10.1177/0269216314551814>

Palliative Phase of Illness does not represent a system to stage the severity of disease, but describes the degree of urgency of the care plan in relation to the patient's situation.

**Palliative Phase of Illness:**

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Mather H, Guo P, Firth A, Davies JM, Sykes N, Landon A, et al. Phase of Illness in palliative care: Cross-sectional analysis of clinical data from community, hospital and hospice patients. Palliative Medicine, 2018 Feb; 32(2): 404-412

**The Integrated Palliative care Outcome Scale (IPOS):**

Murtagh FEM, Ramsenthaler C, Firth A, et al. A Brief, Patient- and Proxy-Reported Outcome Measure in Advanced Illness: Validity, Reliability and Responsiveness of the Integrated Patient Outcome Scale (IPOS). Palliative Medicine, 2019. 33(8):1045-1057.