Enw'r Pwyllgor: Name of Sub-Committee:	Exception Report from Listening and Learning Sub-Committee
Cadeirydd y Pwyllgor: Chair of Sub-Committee:	Chantel Patel, Chair
Cyfnod Adrodd: Reporting Period:	11 October 2023

Materion Ansawdd, Diogelwch a Phrofiad: Quality, Safety & Experience Matters:

The Sub-Committee met on 11 October 2023 and received a number of presentations and individual cases relating to the area of Palliative Care. This was in response to an increased number of concerns about palliative care/end of life and care after death.

All Ombudsman final reports received during the relevant period were also reviewed.

Staff Experience

The Specialist Palliative Care Team presented a case recently investigated by the Public Services Ombudsman for Wales (202203628).

The patient presented with abdominal pain, distention, and vomiting. Patient had previously been diagnosed with Metastatic lung cancer, was previously fully independent and using a Hearing Aid. The patient was stable but deteriorating daily.

The patient was struggling to take oral medication and a pharmacy referral was made; there was also an agreement that the Surgical Team would make a referral to the Specialist Palliative Care Team. The referral was not made and eventually this came from the Lung Cancer Clinical Nurse Specialist.

A telephone consultation was held with the Palliative Care Consultant, as due to COVID restrictions they were unable to see the patient face to face at that time. The Consultant was not made aware of all of the symptoms, such as ongoing vomiting or prescription of a pain medication patch. The patient was hearing impaired and confused and was denying being in pain and not able to make an informed decision.

The Ombudsman's report showed that staff failed to identify the declining health of the patient; the level of discomfort being experienced; and appropriate diagnosis of end of life.

Following these events there is now a Macmillan funding for a Clinical Nurse Specialist in Glangwili Hospital. Training for staff was discussed at a Clinical Governance Meeting between the Surgical and Specialist Palliative Care Teams. The Sub-Committee discussed, at length, the need for improved clarity surrounding the criteria for referrals to be made to the Specialist Palliative Care Team, including information for families around the role of the Team. Posters are visible on walls and sticky labels are available in the notes and are placed on the Out of Hour's team records, but it was recognised that further training was required.

Complaints

Case 9063

The patient was admitted to hospital following a fall and feeling unwell. In the early hours of 23 December, she experienced a cardiac arrest and was successfully resuscitated in Accident and Emergency Department (A&E) and was transferred to Clinical Decisions Unit. The patient was at end of life, and family were concerned about the way in which pain was being managed and felt requests for a medical review were ignored. Concerns were also raised that despite a 'Do Not Attempt Cardio Pulmonary Resuscitation' (DNACPR) in place, the patient's internal cardiac defibrulator (ICD) was left active.

The Specialist Palliative Care Team attended the ward the same morning, and the family cited their professionalism and compassionate care. However, the family were distressed at having to advocate for the team's specialist input and felt that, without family involvement, it may not have been instigated. The patient died later that day. When family were informed of the patient's death by the nurse, they reported a lack of compassion. Their experience worsened further; as the family spent time with the deceased patient, a doctor entered the room and proceeded to verify the death without introducing himself. The family had requested the presence of the chaplain to offer last rights to the patient on a number of occasions. Although the ward had left a message on the Chaplains phone, they had not attempted to contact him on his long-range pager. The patient's clinically qualified family members were distressed at the approach to care of the body by ward staff, and so arranged the body themselves following death to prevent further distress to the other relatives present.

The review acknowledged that the family had felt unsupported to the point of seeking palliative assistance themselves. Although records indicated that analgesia had been given as required prior to the start of a syringe driver, the investigation noted that times were not documented. This report concluded that, without times documented, the effect of the medication on the patient's state of agitation was difficult to assess. The lack of compassion by the doctor carrying out the verification of death was a point the Health Board upheld, and the Health Board agreed that the patient's pre and post death care should have been better. In her first-hand account, the nurse recalled that she had discussed the services of the hospital chaplain with the family but could not advise what actions had been taken.

The complaint and the patient's experience were discussed at the Medical Mortality and Morbidity meeting. Staff were asked to attend 'Care decisions for the last days of death' training. Staff involved were asked to complete reflective learning around the communication issues and mislaid input and output charts. A task and finish group was set up around deactivation of an implantable cardioverter defibrillator (ICD) for end-of-life patients. This included a review of all-Wales practice and was circulated to the Clinical Decisions Unit, Emergency Department, and Coronary Care Unit. In addition, a scoping exercise was undertaken to establish where magnets are held, with onward plans for training, including training of nursing staff.

The case is an example of the way in which a combination of oversights led to additional trauma for the family – issues with clinical and nursing care, communication, compassion, and dignity. The family were informed of the learning in the Health Board's response letter, as improvement in services was their reason for raising the complaint.

Case 9436

The patient attended A&E in Withybush Hospital, arriving by ambulance. At this point she was on Intravenous fluids and oxygen. She had a bowel obstruction related to her endometrial cancer, which was inoperable. The patient remained in A&E and was consulted on her preference to receive end of life care at home or to remain in hospital. She decided to remain in hospital. A referral to Special Palliative Care Team was made.

The patient's daughter reported her own difficulty in receiving updates as the patient deteriorated over the coming days, finding it difficult to obtain a picture of the patient's situation. As the patient began to reach end of life, the patient's daughter was still not informed. When the Special Palliative Care Team visited the patient there was a family member present, who was concerned that Intravenous (IV) fluids and a syringe driver had not been administered. The patient died soon after. A complaint was received, the family being concerned that there had been insufficient pain relief and fluids given to the patient, and that they had not been notified of the severity of the patient's situation. Particularly, the patient's daughter reported a misleading picture being given on her last call to the hospital, the evening the patient died.

Nurses had documented on two occasions that they had asked a doctor to call the family to inform them of the patient's decline, but family stated that they had not been called, and were distressed at missing the opportunity to spend final moments with the patient. The family maintained that throughout the patient's three-day stay in hospital, they had not been informed of the severity of the situation and that she was at end of life, adding to their distress.

The family remain dissatisfied with the response and are affected by the communication issues surrounding the patient's death. The opportunity they have missed to spend final moments with the patient has made their bereavement more intense. A meeting has been requested with the service to discuss the report and some of the points that they question. The family have approached the Ombudsman for advice, although the Health Board has not yet been approached for comment. The case is an example of the way in which basic oversights in communication can have a lasting impact on families and their ability to recover from bereavement.

On review of the complaints cases presented, the Sub-Committee discussed the importance of a timely referral to Specialist Palliative Care Team. Improved communication between departments and with the families was a priority, as well as improved interactions with the bereaved family and next of kin, pre and post death care.

Palliative Care Strategy

The Sub-Committee received an update on progress with implementation of the Health Board's Palliative Care Strategy. The Sub-Committee was concerned to note limited progress in some areas, due to investment in a triumvirate management team to draw together palliative care into one service across the Hywel Dda community.

It was agreed to establish a meeting outside of the Sub-Committee to discuss the issues raised at the meeting; and to refer these to the Palliative Care Strategic Group to review the themes arising, including:

- Communication and training re role Specialist Palliative Care Team;
- Specialist Palliative Care Team criteria and awareness raising;
- Communication to patients about the provision of services, in particular the relationship between Swansea Bay HB Specialist Oncology Service;
- Patient support, involvement and understanding of their treatment plan;
- Pre and post treatment surgical support;
- Perceived delay in diagnosis and commencing cancer treatment;
- A Regional Collaboration for Health (ARCH) review of the cancer pathways;
- Support in receiving diagnosis and the communication aspects of breaking bad news.

FamCare Audit update

The FamCare Audit's aim is to provide an anonymous feedback questionnaire compiled nationally and collect feedback for palliative care. The National Audit for the Care at the end of life (NACEL) is already available and has years' worth of data around this area was available. The Specialist Palliative Care Team would present the results of the audit to the Listening and Learning Sub-Committee when available. A palliative care survey was also available to the service within the Civica Patient Experience System.

Public Services Ombudsman

Four cases that had been investigated by the Public Services Ombudsman were received by the Sub-Committee (711; 18575; 18985; 1556). One was up held two were partially upheld and one was not upheld. All actions were progressing and within the target timeframes.

The Sub-Committee received and discussed the Ombudsman's Annual Letter 2022-23.

The Sub- Committee spent time discussing the Ground-hog Day 2 Ombudsman's report. The key themes of defensiveness; poor communication with complainant's' timeliness of responses; and lack of objectivity – leading to insufficiently robust investigations were discussed.

Putting Things Right Action Plan

The Sub-Committee received an action plan covering the recommendations contained in the following reports: Ombudsman's annual letter; groundhog day 2 report; Welsh Risk Pool assessment 2022-23; and internal audit reports for lessons learnt and patient experience. This action plan would be closely monitored by the Sub-Committee and any areas of concern with compliance would be escalated to the Quality, Safety and Experience Committee as appropriate.

Inquest Guidance

Updated Inquest Guidance for Staff was approved by the Sub-Committee.

Risgiau:
Risks (include Reference to Risk Register reference):

- Implementation of Palliative Care Strategy

- Medical Records Management - access to records; quality of the record; and disclosure processes (involving redaction and scanning). This was a risk to the management of concerns and compliance with the disclosure requirements for proceedings and legal claims.

Gwella Ansawdd:
Quality Improvement:

The identified actions for quality improvement from review of cases that remain on the Sub-Committee action log are as follows:

- Follow up, monitoring and action of all test results.
- Delaying in conveying test results due to provision of paper results
- Improvements in relation to communication.
- Medical records management and record keeping (including scanning and disclosure).
- Review of the discharge process.
- Issue an alert to the manufacture of the oximeter machine, due to two safety incidents
- Ensure appropriate actions are being undertaken in response to any incidents involving absconding patients.
- Care After Death/Bereavement – improvement in communication and revision of Care After Death policy.

Argymhelliad:
Recommendation:

- Discuss whether the assurance and actions taken by the Sub-Committee to mitigate the risks are adequate to address the learning from previous events and improve the arrangements for the care of patients in future.

Dyddiad y Cyfarfod Pwyllgor Nesaf:
Date of Next Sub- Committee Meeting: January 2024