

WELSH HEALTH CIRCULAR



Llywodraeth Cymru
Welsh Government

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For Action by:
Chief Executives

Action required by:
Immediate

Sender:
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Enclosure(s): Letter from Andrew Goodall, Principles and Guidance document

Yr Adran Iechyd a Gwasanaethau Cymdeithasol
Cyfarwyddwr Cyffredinol • Prif Weithredwr, GIG Cymru

Department for Health and Social Services
Director General • Chief Executive, NHS Wales



Llywodraeth Cymru
Welsh Government

Chief Executives – NHS Local Health Boards
Chief Executives – Velindre NHS Trust

Our Ref: WHC/001/14

23 September 2014

Dear Colleague

Principles and Guidance – Key Workers for Cancer Patients

You will be aware that in April 2011 a commitment was made by the Welsh Government that all Cancer patients should have an identified Key Worker. At the time no guidance was issued and Organisations have since developed their own operational guidance to support this role. However, despite the 2013 Patient Experience Survey clearly demonstrating the benefit of key workers, with those with a key worker in place giving consistently higher satisfaction scores, the report indicated that only 66% of patients had a key worker and there was large variation between Organisations and tumour groups.

Whilst it is clear that many patients have a Key Worker in place, the inconsistency reported in the Patient Experience Survey is of concern.

The Principles and Guidance document attached to this letter has now been produced following consultation with Health Boards, Velindre NHS Trust, members of the Cancer Implementation Group (CIG), cancer patients and carers. The document was signed off by the CIG on 17th September. The expectation of the Group is through the implementation of these Principles we can now ensure greater consistency in the support to individuals provided by Key Workers.

The expectation of Welsh Government is that action will now be taken to ensure more consistent delivery of the Key Worker policy in line with these documents. This more consistent guidance should help.

Monitoring of the Key Worker role will be undertaken through a number of routes, we will be asking the cancer networks to audit implementation and to include discussion of Key Workers as part of the Peer Review process. We will also be seeking the views of patients

via the next Patient Experience Survey. You may also wish to consider how you assure yourselves of progress at a local level.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Andrew Goodall'. The signature is fluid and cursive, with the first name 'Andrew' and the last name 'Goodall' clearly distinguishable.

Dr Andrew Goodall

Principles and Guidance - Key Workers for Cancer Patients

Principles

1. Key Worker definition:
“a person who, with the patient’s consent and agreement, takes a key role in coordinating the patient’s care and promoting continuity, ensuring the patient knows who to access for information and advice” (NICE 2004)
2. One person who acts as a coordinator and facilitates access to information, care, liaison and support throughout the cancer journey, between health professionals and the patient, including the relevant primary care teams, to ensure continuity of care and a seamless service. This person may change during the Cancer journey but changes must be kept to a minimum.
3. Takes the initial role in assessing and providing support that is appropriate to the context and sensitive to meet the patient/carer and/or family's needs, enabling them to help themselves by signposting appropriately or facilitating access to additional support from other healthcare professionals or on broader holistic needs e.g. financial or welfare advice.
4. Ensures an appropriate Care plan is agreed with the patient having already been a key part of discussions in the creation of the plan. Ensures the plan is then communicated to others involved in the patient’s care, particularly when the patient is transitioning between primary, secondary and specialist care.
5. Communicates and co-ordinates information to patients and carers, evaluating their levels of understanding and utilising a range of skills/techniques to overcome any communication difficulties.
6. The patient must be given the name, contact details and informed of the role of the Key Worker at diagnosis and following subsequent handovers of care.
7. The Key Worker must be contactable and responsive. However, the role is not an emergency contact and therefore is not expected to be available 24/7. The Key Worker does not replace clinical experts in the delivery of the cancer pathway.

Guidance

- **Who should carry out the Key Worker role?**

When being treated by the cancer Multi Disciplinary Team (MDT), the key worker is likely to be an existing member of the MDT and could be the Clinical Nurse Specialist (CNS) or a rehabilitation specialist.

When not under active management by the cancer MDT, the Key Worker would be a member of the primary care team. The involvement of the GP is also critical as many patients living with cancer are also living with at least 2 if not more other chronic conditions.

For the majority of cancers it is likely that the CNS will perform the role of Key Worker. Where a CNS is not available, the Key Worker should be another relevant professional as identified by the MDT

- **Allocating the key worker.**

It is envisaged that Key workers will be reviewed at key points in the patient's cancer journey. These key points are:

- Around the time of diagnosis
- Commencement of treatment
- Completion of the primary treatment plan
- Disease recurrence
- The point of recognition of incurability

The key worker may change, as patient's needs change to ensure that the patient is being guided by the most appropriate health care professional. A change of key worker must be fully documented and all the relevant professionals informed. Changes must be kept to a minimum.

Key Worker best practice indicates that the individual should have advanced communication and/or counselling skills.

It is vital that the Key Worker must have appropriate knowledge or can source the appropriate information to meet the needs of the patient at the time.

- **Standards**

- All Cancer patients must have an allocated Key Worker
- The name of the Key Worker must be recorded in the patient's notes
- The name of the Key Worker must be recorded on CANISC.
- The name of the Key Worker must be passed to the patients GP
- Patients must be given a completed Key Worker Card with the contact details for their Key Worker, as well as a patient information leaflet describing the role of the Key Worker.

- **Key Worker Job Role**

- To initiate and participate in cancer and palliative care MDT discussions and case conferences with all professionals involved in the delivery of patient care.
- To act as an advocate for the patient.
- To act in a way that supports the patient to manage their own care
- To be accessible and responsive to the patient.
- To act as a communication resource and co-ordinator for other members of the multi-professional team in the care of the key worker's patient caseload.
- In conjunction with the MDT, to provide patients with comprehensive information on the options available to them for treatment and care.
- To co-ordinate the onward referral of patient and/or family members to appropriate clinical or support services.
- To utilise support strategies and interventions available, initiate appropriate referrals when caring for patients with complex needs, e.g. patient exhibiting denial/anger following a cancer diagnosis, adverse reactions to alteration in body image.
- To demonstrate knowledge of holistic cancer care relating to areas such as screening, curative and palliative treatment, spiritual care, aspects of nutrition and pharmacology, rehabilitation, discharge and collaborative working.
- To demonstrate a comprehensive knowledge of the assessment, care, management support, training education and information requirements for patients receiving chemotherapy, radiotherapy or having surgery and their carers and treatment for related complications across the care pathway for the particular specialty area.
- To signpost to (or provide where required) information, education and relevant telephone contacts to patients and carers regarding the procedures and side effects of chemotherapy and general radiotherapy such as fatigue and skin reactions.
- To signpost to local support groups or appropriate websites which can provide information/support to the patient and carer/family.
- To signpost to information and relevant contacts for advice on finances and welfare benefits
- To be knowledgeable about the management of common side effects (and informing patients accordingly) for treatments associated with the client group encountered in their practice.
- To be aware of local contact arrangements in the event of patients experiencing unwanted side-effects.
- To effectively liaise across organisational and geographical boundaries where required to meet the needs of the patient.
- To demonstrate knowledge to prepare, inform and educate patients/carers for survivorship, utilising and signposting to Third Sector for support and

information during and at the end of treatment and where applicable, primary care personnel regarding any associated care requirements, symptom management and contact details on discharge.