

# Empowering patients

*A novel tool to help cancer patients manage their symptoms*

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Shelley Dolan (left) and a colleague

## WISECARE — a virtual European nursing project

**W**ISECARE is an exciting clinical nursing research project that seeks to involve cancer patients more in their own

care, and also to increase European nursing collaboration, leading to improved nursing knowledge and practice. Also known as the Workflow Information Systems for European Cancer Care project, WISECARE uses information technology (IT) in a creative way to enable patients and nurses to gain feedback and regular updates on symptom management in graphic form.

The first phase of the WISECARE study began in 1997 and was funded by the European Commission who worked closely with the European Oncology Nursing Society. Following completion of this phase in 1999, we commenced the second phase WISECARE+ in June 2001 which is being funded by The Royal Marsden Trust Funds.

The main aims of the WISECARE+ project are to improve patient outcomes by reducing the impact of symptoms whilst cancer patients are receiving chemotherapy, and also to create a virtual organisation of cancer nurses across Europe who can share and promote knowledge and evidence-based care.

We are:

- involving people with cancer in the assessment and evaluation of their own symptoms, and then equipping them with self-care guidelines they can use to reduce the impact of the symptoms;
- encouraging nurses across Europe without a common language to collaborate and compare the evidence for nursing interventions;
- increasing the knowledge and evidence base on nursing interventions for the symptoms of cancer chemotherapy;

- increasing the support for patients whilst they are receiving chemotherapy at home;
- establishing the correlation between a patient's symptoms and biological parameters;
- comparing patient symptom experiences between diagnostic groups;
- exploring the impact of nursing skill mix and cancer nursing education on patient outcomes.

## WISETOOL makes data available internationally

WISETOOL is the IT data and information tool. One of the boundaries to the increased collaboration of cancer nurses across Europe is the lack of a common language. In the past this has necessitated the use of translating tools. However, WISETOOL incorporates several languages and, similarly to an automatic bank teller machine, asks which language should be used. This feature enables a nurse to enter or retrieve data in his or her own language. It also means, for example, that English nurses can explore data from WISECARE+ sites in other countries.

Before patient recruitment started, every WISECARE+ site submitted their chemotherapy protocols used for each of the following diagnostic groups: lung cancer, breast cancer, colorectal cancer, sarcoma, leukaemia, lymphoma and ovarian cancer. All sites also forwarded their nursing intervention protocols on how to relieve nausea and vomiting, manage fatigue and minimise oral health problems.

All the latest guidelines and WISECARE+ information are held in the WISEWEB repository on the Internet – meaning the data can be accessed from anywhere (providing there is an Internet connection).

## Our current study — WISECARE+

Currently six WISECARE+ sites are in operation across Europe in the following locations: Ayrshire and Arran Acute Hospitals NHS Trust; North Glasgow University Hospitals Trust; The Royal Marsden NHS Trust; St James' Hospital, Belfast; The Aalborg Hospital, Aalborg, Denmark; and The Slovenia Hospital, Ljubljana, Slovenia.

All patients recruited to the WISECARE+ study have a form of cancer, which can be categorised into one of the

diagnostic groups mentioned earlier, and will be about to start chemotherapy for their first time. In addition, all patients are over 18 years of age, are aware of their diagnosis of cancer, are able to give informed consent and are able to read and write in the native language of the country in which they reside.

Nurses use WISETOOL to randomise patients to one of two groups. In the first phase of the study, patients in Group 1 received local care and completed WISECARE+ assessment questionnaires. Patients in Group 2, on the other hand, received the same interventions as Group 1 but were also given self-care guidelines. All relevant nursing personnel were introduced to the same set of evidence-based guidelines. This first phase was a period for participants to become familiar with project protocol and we collected no data.

Subsequently, in the second phase of the study, we gave all patients self-care guidelines and WISECARE+ questionnaires, and the nurses provided evidence-based care.

### How do patients record their symptoms?

During each cycle of chemotherapy treatment, the patient completes a WISECARE+ questionnaire once a day for 14 days, commencing on day 1 of the chemotherapy regimen.

The WISECARE+ assessment questionnaires are designed to be short and easy to use. They ask questions about the common problems patients experience during chemotherapy, such as nausea, vomiting and fatigue and effects on oral health.

Each patient is asked to answer yes or no as to whether they have experienced each of the above symptoms. They are subsequently asked to evaluate the severity of the symptom and its impact, in other words the distress caused that day by that symptom. To assess their oral health, a detailed oral assessment section of the questionnaire encourages patients to inspect their lips, tongue and gums daily for any problems.

After the section for recording symptoms is a list of self-care activities, and the patient ticks all activities employed that day. Space is also provided for patients to report any additional activities they found useful and any other symptoms they experienced during that day.

Patients post their completed questionnaires in prepaid envelopes to their clinical site. We also ask a random selection of patients to complete an extra questionnaire that explores their perception of the WISECARE+ process.

### Correlating symptoms with biological parameters

One of the subsidiary aims in our project is to map the results of patients' blood tests against their symptoms, to

see whether there are any correlations. Hence we ask patients for a blood sample on day 1 and day 9 or 10 of the study, for use in full blood cell count, biochemistry and liver function tests. These data are also entered into WISETOOL.

### Individual patient feedback

We enter all patient data from the questionnaires into WISETOOL and regularly export the accrued dataset to the study data management and analysis team.

Each time data from a patient's 14-day cycle are entered into WISETOOL the information is instantly converted into a graphic representation of their individual symptom experience over time (Figure 1). Accordingly, when patients return to the clinic they can receive feedback in graphical form either as a paper printout or on a computer screen in the clinic.

Several patients have remarked that they find this type of graphic representation very useful during consultations with medical and nursing teams. Additionally, patients have stated that sometimes at their consultation it is difficult to recall their symptoms during the previous days – in these instances the graphical feedback provided by WISETOOL is invaluable.

### Global feedback to hospital sites

At regular intervals WISETOOL provides global feedback graphs to the WISECARE+ hospitals so that comparisons can be made across both sites and diagnostic groups (Figure 2).

### What have we found so far?

We are now in the second phase of data collection in the WISECARE+ project. Following the distribution of the clinical evidence-based guidelines to nursing personnel, we started recruiting patients again in March 2003.

Even at this early stage, patients are benefiting from improved self-care. Many patients have commented both verbally and in writing on their questionnaires how much they have enjoyed feeling more involved and in control of

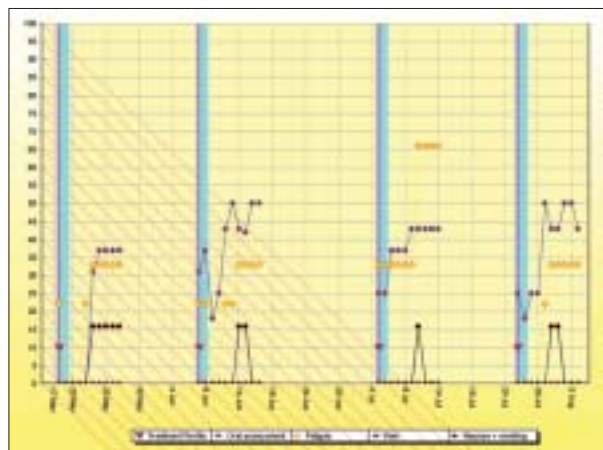


Figure 1 Graphic representation in WISETOOL of an individual patient's symptom experience over time. Each graph line represents a different symptom (eg fatigue, pain, nausea + vomiting).

their care. Some patients, in their own words, have been keen to do something themselves to help and have viewed the daily check of their oral health as a positive step.

For nurses too several positive aspects have emerged from the study. For some practising staff nurses, for example, this is their first active involvement in nursing research – involving both clinical and research nurses will reduce the gap between nursing research and nursing practice. The use of evidence-based guidelines also ensures that nurses develop their knowledge of the interventions that can be used to minimise and treat the symptoms of cancer chemotherapy.

### Developing WISECARE in the future

A WISECARE pilot study, also funded by The Royal Marsden Trust Funds, looking at the experience of adolescents with cancer has commenced in the UK.

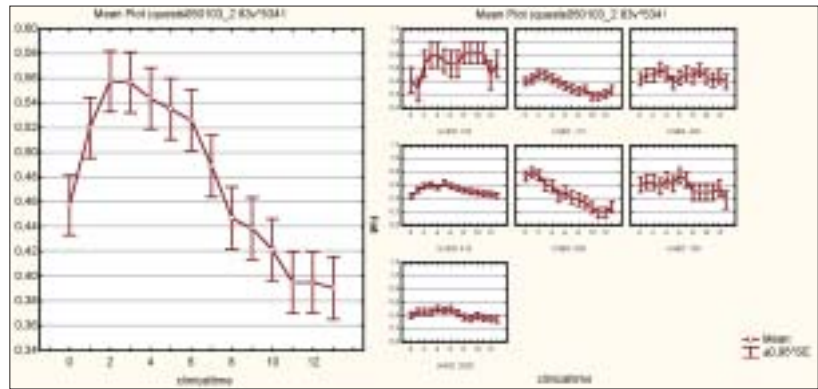


Figure 2. Example of comparative global feedback graphs exported from WISETOOL. This example shows data patients recorded on the level of fatigue experienced while taking chemotherapy.

With developments in IT we hope that in the future patients will be able to access WISETOOL in their own homes. Patients could then input their questionnaire data automatically into WISETOOL and subsequently receive instant feedback without having to involve a third party. These patients with cancer would be further empowered to manage their own symptoms.