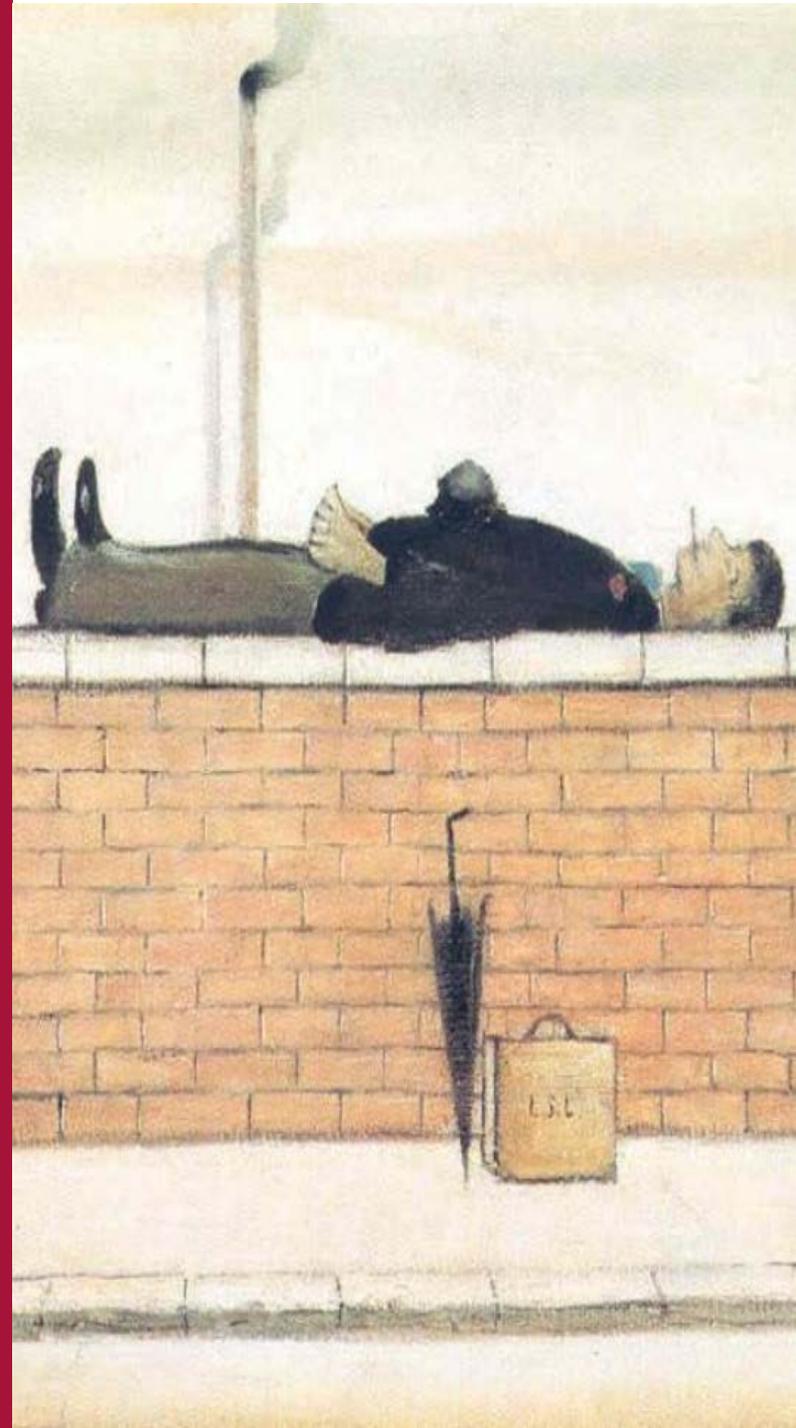


Work is an important – and neglected – issue in palliative care

Dr Gail Eva

**13th Australian Palliative Care Conference
Melbourne
2nd September 2015**



Work support for people with cancer in the UK

Who will help us
to return to
work?



Cancer
services

*Focussed on
treatment*



Occupational
health

*Limited to large
employers*



NHS rehab
services

*Focussed on
hospital discharge*



DWP
programmes

*Concerned with
benefit recipients*

The benefits of work for people who are ill and disabled

- Helps to promote recovery and rehabilitation.
- Leads to better health outcomes.
- Minimises the harmful physical, mental and social effects of long-term sickness absence.
- Reduces the risk of long-term incapacity.
- Promotes full participation in society, independence and human rights.
- Reduces poverty.
- Improves quality of life and well-being.



Waddell B, Burton K (2006) Is work good for your health and well-being? London: TSO.

Two research studies

NCSI Vocational Rehabilitation Pilot Project[§]

- Realist evaluation of seven cancer VR services
- April 2010 – July 2012
- Funding: NCSI £158,000
- Ethics approval: REC Ref: 11/H0716/5

The REJOIN Study (REhabilitation for Job and Occupational INdependence)

- Co-investigators: Diane Playford, Julie Barber, Ramon Luengo-Fernandez, Bee Wee
- January 2012 – December 2015
- Funding: NIHR £354,765.00
- Ethics approval: REC Ref: 12/LO/1925


National Institute for
Health Research

**WE ARE
MACMILLAN.**
CANCER SUPPORT

National Cancer
Survivorship Initiative

 **Brunel**
University
London





[§]Eva G, Playford D, Sach T, Barton, Risebro H, Radford K, Burton C (2012) *Thinking positively about work: delivering work support and vocational rehabilitation for people with cancer*. London: National Cancer Survivorship Initiative.

NCSI Vocational Rehabilitation Pilot Project

Aim

To identify a model of cancer VR capable of being widely implemented with good outcomes.

Method of investigation

Realistic Evaluation (Pawson and Tilley 1997) was used to develop explanatory accounts of 'what works' in cancer vocational rehabilitation.

Data collection and analysis

- *Service structure and delivery*: 4 interviews and 7 focus groups with 22 service providers; standardised service data templates (330 returned); content analysis of final reports.
- *Definition, content and competencies for cancer VR*: Consensus development using a modified Nominal Group Technique.
- *Perspectives of service users*: In-depth interviews with 25 service users.
- *Health economic data*: Expenditure – patient-related staff costs and support costs; service users invited to complete EuroQOL EQ-5D-3L; modified Client Services Receipt Inventory. 143 returns at baseline, 86 at six months (60.1% response rate)

The REJOIN study – developing and testing a cancer-specific VR intervention

Aim

To determine the feasibility of a randomised controlled trial to evaluate the clinical and cost effectiveness of a cancer-specific VR intervention (the REJOIN intervention – REhabilitation for Job and Occupational INdependence), delivered in the context of routine clinical practice.

Method of investigation

Feasibility randomised controlled trial.

Data collection and analysis

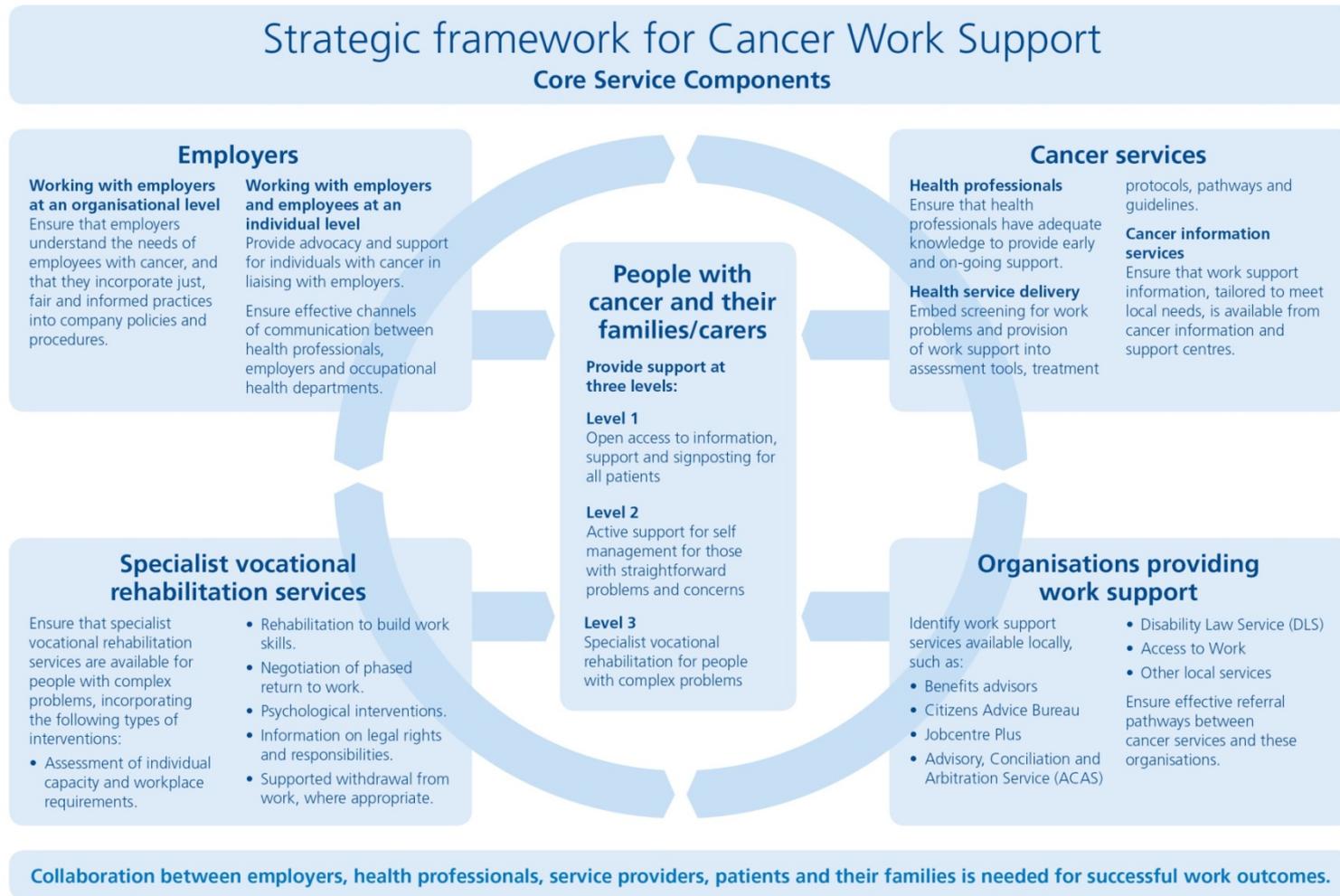
- 60 participants recruited from 8 cancer treatment centres over 24 months
- Evaluation of acceptability of therapist training and intervention delivery.
- Participant measures: work status and duration of sick leave, cost effectiveness, mood, fatigue, cognition and fatigue at baseline, 3, 6 and 12 months.
- Nested qualitative study examining helpful and unhelp support received by participants in both intervention and control groups.

NCSI VR Pilot – overview of findings

- 597 people were referred across all pilot sites. Analysis of 330 service data templates: ‘positive’ work outcomes recorded for 46.4%, i.e. sick leave → full/modified work; remained in work; unemployed → working.
- Cost of VR intervention: weighted average per person cost of £842.23 (range £384.86 - £1590.02).
- Contact time per person: 4.8 hours – 8.4 hours.
- Strategic framework for providing adequate work support for people living with and beyond cancer.
- Ways in which health professionals’ interactions with service-users both help and hinder the achievement of optimal work outcomes.
- Needs of people living with advanced disease.

Strategic framework for cancer work support

Figure 1: Strategic model of cancer work support



Strategic framework for cancer work support

Employers



Cancer services



People
living
with
cancer



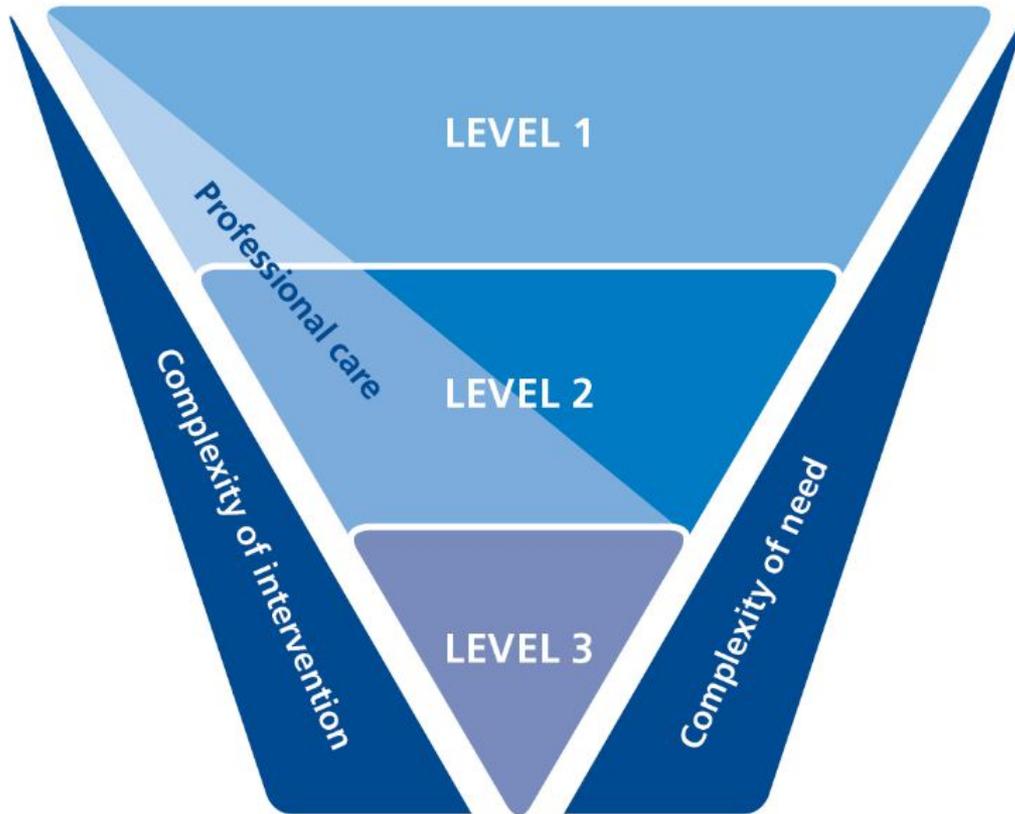
Specialist vocational
rehabilitation
services



Organisations
providing work
support

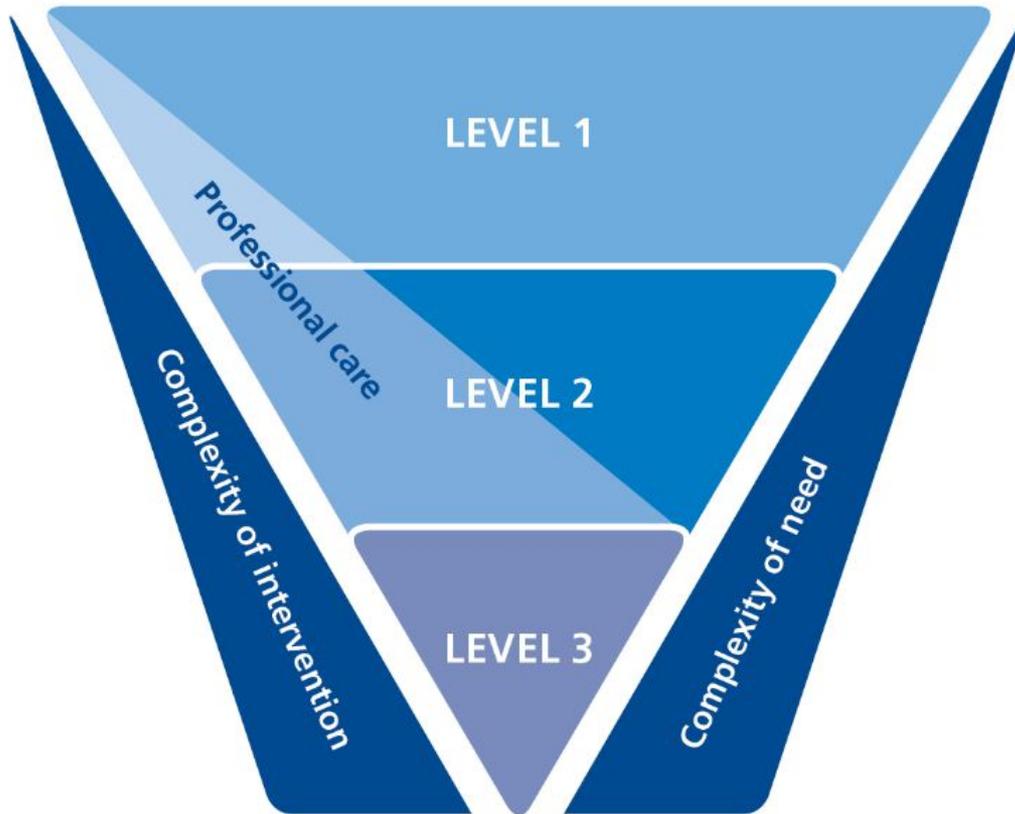


Levels of support required



Eva G, Playford D, Sach T, Barton, Risebro H, Radford K, Burton C (2012) Thinking positively about work: delivering work support and vocational rehabilitation for people with cancer. London: National Cancer Survivorship Initiative.

Levels of support required



Level 1:

Everyone who works or have the potential to work



Level 2:

People with 'straightforward' problems

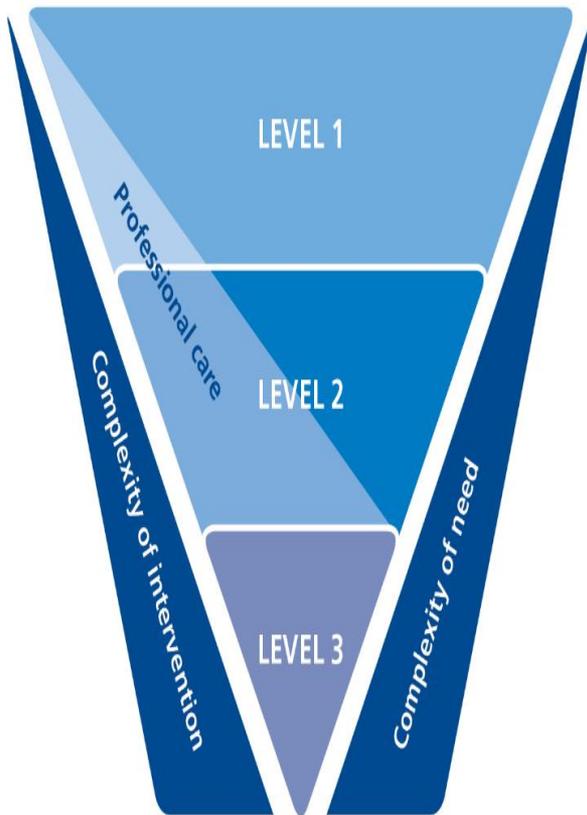


Level 3:

People with complex problems

Eva G, Playford D, Sach T, Barton, Risebro H, Radford K, Burton C (2012) Thinking positively about work: delivering work support and vocational rehabilitation for people with cancer. London: National Cancer Survivorship Initiative.

Levels of support required



Level 1:
Everyone who works or
have the potential to work

Putting work on
the agenda:
**'positive
messages',
signposting**



Level 2:
People with
'straightforward' problems

**Tailored
information,
advice and support**



Level 3:
People with complex
problems

**Specialist
vocational
rehabilitation**

Eva G, Playford D, Sach T, Barton, Risebro H, Radford K, Burton C (2012) Thinking positively about work: delivering work support and vocational rehabilitation for people with cancer. London: National Cancer Survivorship Initiative.

Work issues identified by service-users

- For some people with life-limiting illness, work is important. It supports a sense of competence and normality and legacy and is a welcome distraction.
- Uncertainty and the difficulty of planning for the future has consequences for remaining at work.
- There is a tension between the person's health needs and the employer's business needs.
- What does it mean to be 'fit for work'?
- Negotiation skills and the willingness to compromise are important.
- (People make assumptions about) being a burden.
- Achieving a positive withdrawal from work, where this is the best option.

Work is important: competence, normality, distraction, legacy

*You need to have a sense of value, to
be needed, and that's why I like my job.*

*I get a lot of good feedback from my
clients. I can see the difference I make
in some of their lives and that helps
me to feel that I'm leaving something
worthwhile behind.'*

Wendy, social worker



Uncertainty and planning

We found out [after the surgery] that it was a Grade 3 anaplastic astrocytoma. Before the operation the surgeons were very positive – it was, ‘Get over this, get back to work.’ Although they must have known even at that stage that it was going to take months even if everything went bang according to plan. It’s sort of... it’s as if they withhold bad news, isn’t it?

Richard, accountant



Health needs vs business needs

'The doctor told me I had Stage III cancer and we discussed what kind of treatment I should have. I immediately told my manager what my diagnosis was, and she said, 'Does that mean you're going to die? How long have you got?' Which I thought was, you know, superb. I said, 'I don't know. I'm telling you as much as I know.'

Wendy, social worker

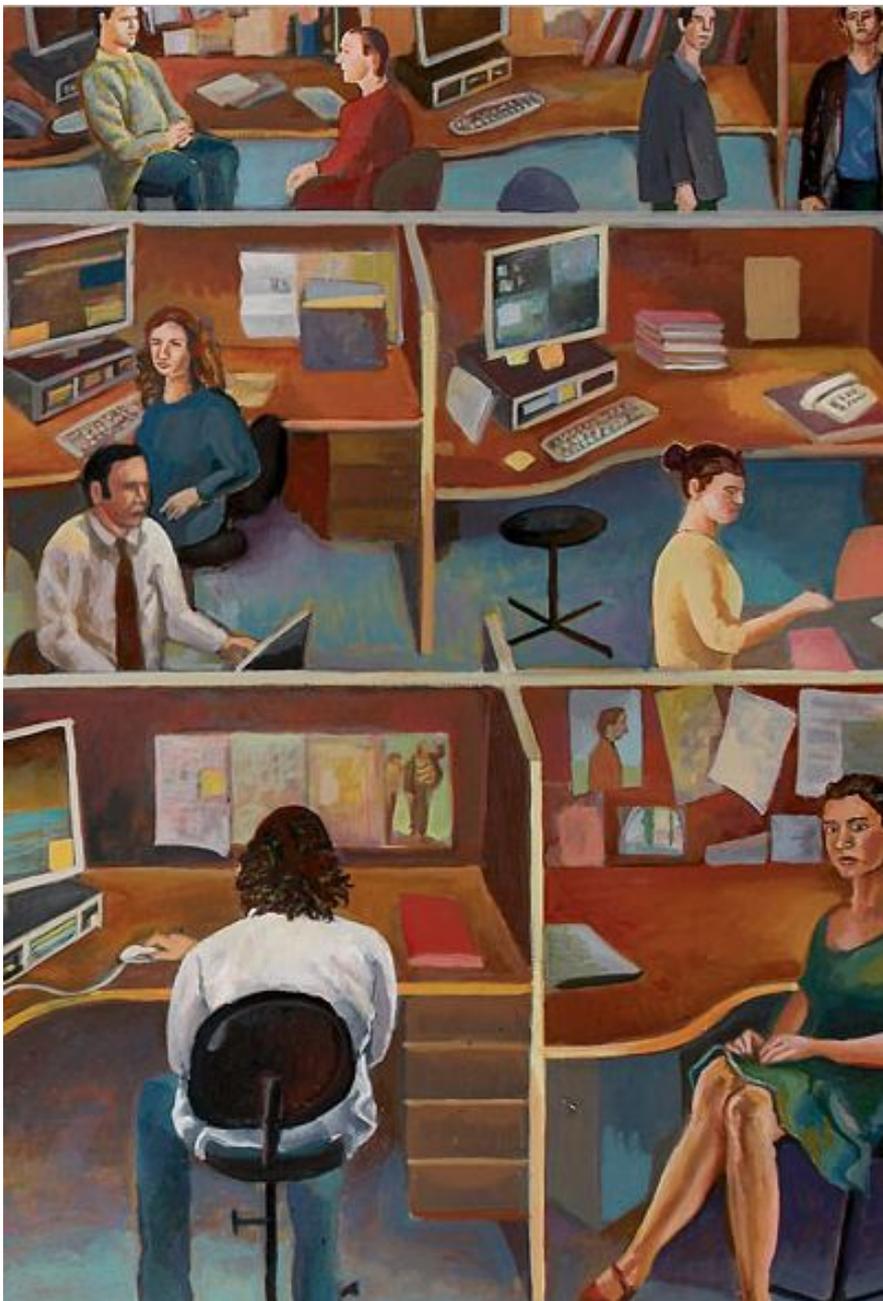
Fit for work

Nobody told me when I could go back to work. I think I was looking for someone to say, it's time for you to get your act together and get back to work, but the doctors were leaving it up to me and work were basically saying, we don't want you back until you're well.'

The organisation changed a lot while I was away and my boss, a new boss, a man I did not know, basically said, 'Come back to work when you're ready.'

They were accommodating and had the best of intentions but they were actually not very helpful.

James, company director



Being able to negotiate

'I was struggling with pain and I was taking more oramorph at work. I made an error and the company disciplined me for it. Because I was having the vocational rehabilitation support, it gave me a lot of information that I wasn't aware of. Like it didn't occur to me that I would be, well, classed as disabled. Once I knew I had rights, I put the information about the Equality Act on the table with my manager and HR and at that point they did a complete turnaround and said, 'Look, we're really sorry that we put you through this.'

Martin, operations manager





(Assumptions about) being a burden

I felt bad about all the time I had taken off. My manager was very supportive and sympathetic. We talked about a phased return and how they could arrange light duties, but getting that organised was going to take so much effort and involve so many meetings, and my colleagues would have to fill in for me. When she said, 'Are you sure this is what you want?' I thought 'I could just resign. That might be the easiest thing for everyone.'

Mark, cook

A positive withdrawal from work

'I used to love my job. But while I was having chemotherapy they changed it all and they put me in the call centre. Well my memory is so bad now because of the brain tumours [secondary to lung cancer] and there was a terrible amount of stuff that you had to learn. I couldn't cope with it so I left. I might go and do some voluntary work in the charity shops but I don't know.'

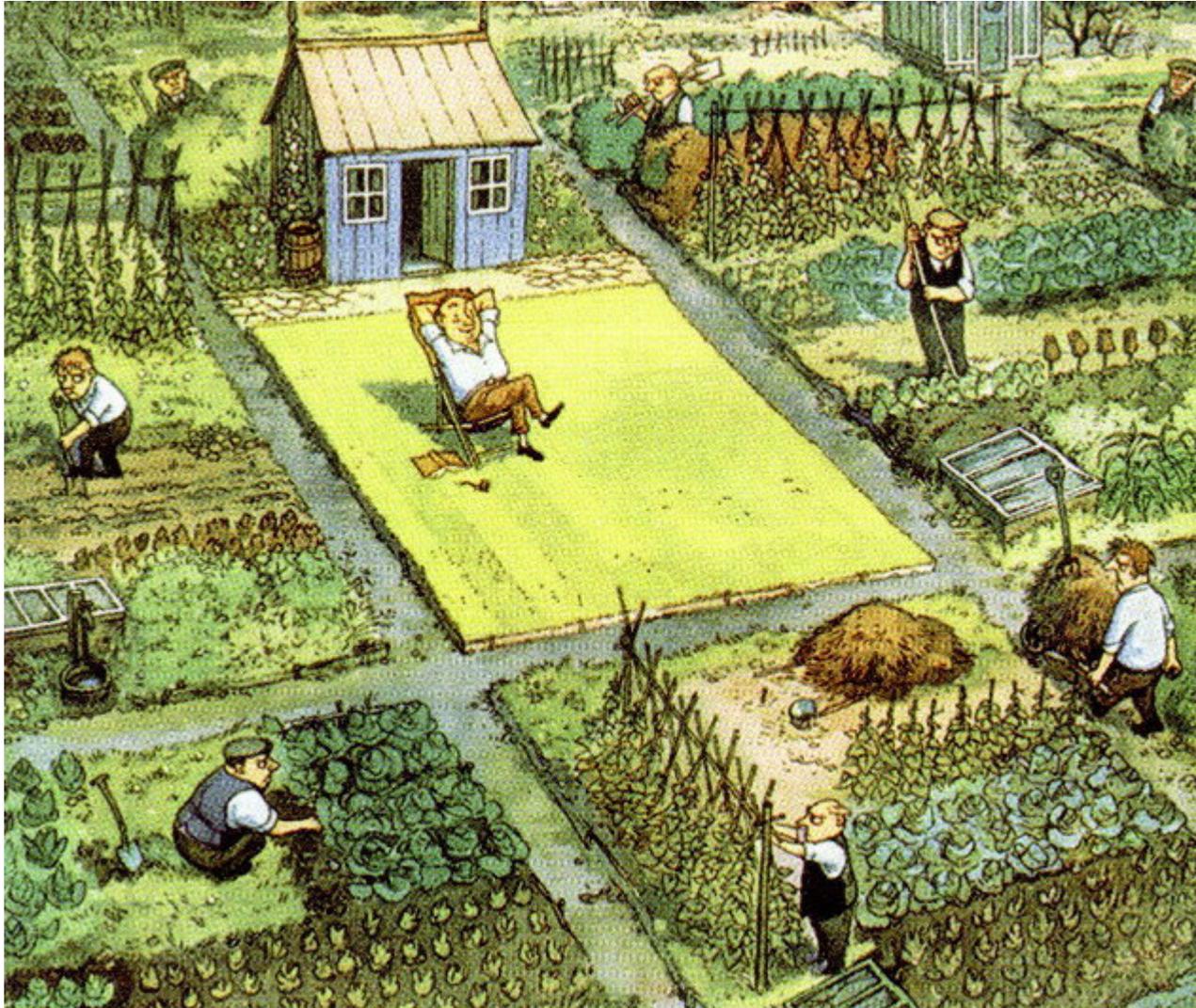
Nora, sheltered housing warden



Some brief discussion points

- What constitutes a good work outcome?
- Distinguishing between ‘work’ and ‘good work’.
- Attitudes to work and how this shapes our responses.
- A need to know the answers.

What constitutes a good work outcome?



“Work is not always required of a person. There is such a thing as a sacred idleness, the cultivation of which is now fearfully neglected.”

George MacDonald.

1824 – 1905

What constitutes a good work outcome?

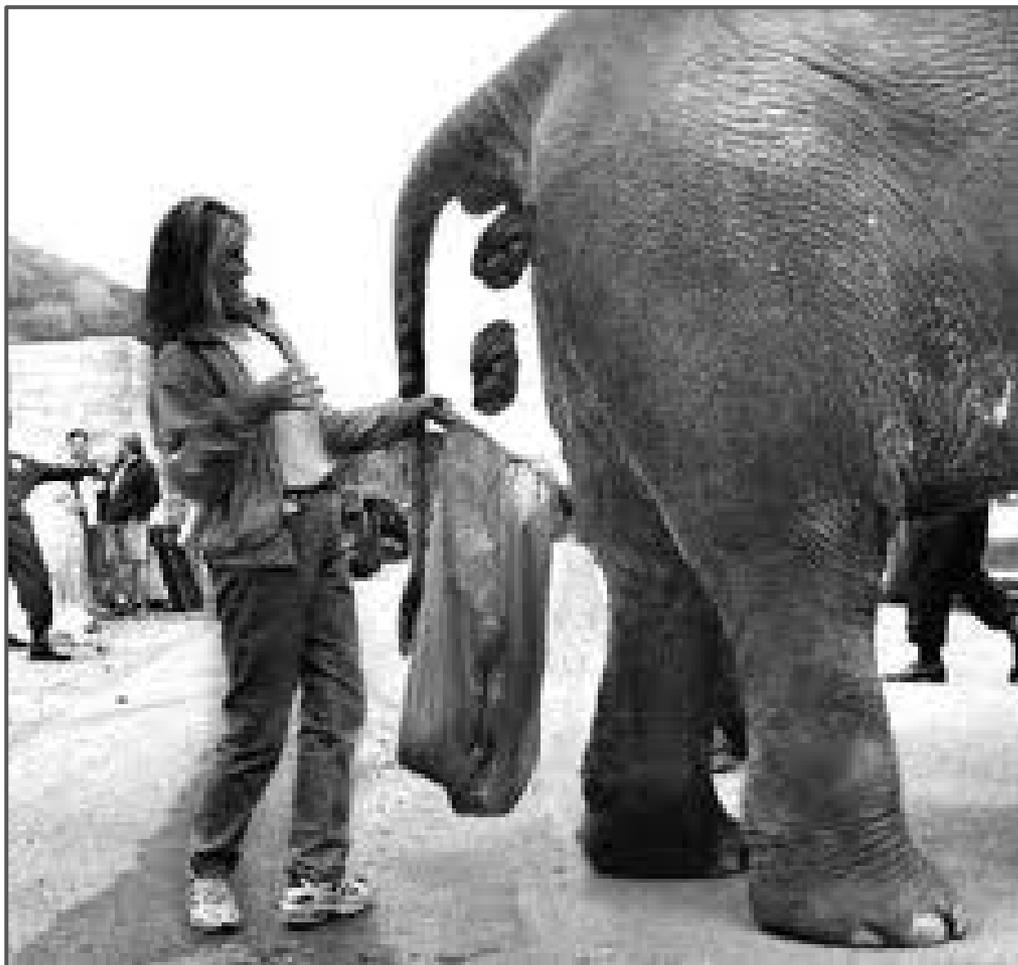


- Different stakeholders have different views on this.
- Unwanted / undesirable / unnecessary withdrawal from work.

Work is good for us



But some jobs are horrible...



sense of
identity

social
connections

self esteem,
confidence

competence

structures
the day

vs

stressful

depressing

boring

demoralising

bullying

'Good work' is characterised by:

Reasonable job security.

Work that is not monotonous.

A degree of autonomy, control and task discretion.

The opportunity to be creative.

A reasonable balance between effort and reward.

Having the proper skills to do the job well.

Support to cope in periods of intense pressure.

A sufficiently safe and healthy working environment.

Strong workplace relationships.

Attention to a decent work-life balance.



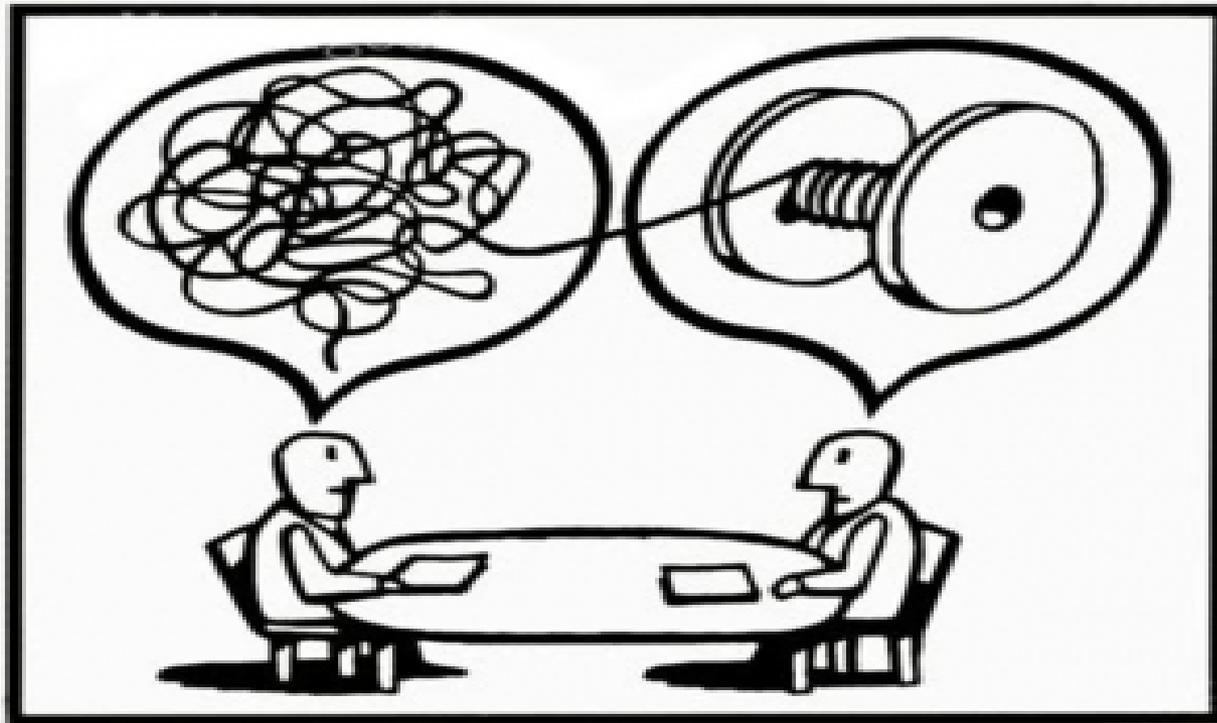
Coats D, Lehki R (2008) Good work: job quality in a changing economy. London: The Work Foundation.

Attitudes to work

People with life-limiting illness might want 'to put work on hold for the time being.'

If health professionals perceive work as a worry or a burden, we feel we are being supportive by encouraging people to do this.

“If I don’t know the answer I can’t help you”



Practice implications

- Acknowledge and identify areas of uncertainty.
- Tease out the assumptions being made.
- Determine person's capabilities and match these against the demands of the job.
- Identify the pros and cons of possible decisions.
- Consider changes that can be made to facilitate continuing to work.
- Talk to employers.
- Identify expert advice needed and facilitate its provision.
- Support leaving work positively, where appropriate, with attention to dignity and self-esteem.
- Provide active support for new activities and roles.

Contact details



gail.eva@brunel.ac.uk



www.facebook.com/gail.eva

www.twitter.com/gaileva

Palliative Rehabilitation Group on Facebook:

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