Report

People with cancer and an intellectual disability: an international issue with local significance

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Cancer Care Research Centre
Linking reality with science

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Introduction

The workshop *People with cancer and an intellectual disability: an international issue with local significance* took place in Edinburgh on February 22nd 2008.

The workshop was organised by the Centre for the Older Person's Agenda, Queen Margaret University and the Cancer Care Research Centre, University of Stirling.

The workshop aims were to engage in a sharing of knowledge and experience and through discussion to drive forward change by creating agendas for policy, practice and research.

The objectives were to:

1. present a range of current perspectives on policy, practice and research in cancer care for people with intellectual disabilities; sharing international perspectives

2. identify and explore key issues

3. share current practice and research concerns based on practitioner and personal experiences of cancer care

4. to identify what a community of researcher, policy makers and practitioners would look like

5. develop practice and research agendas with action plans for taking such agendas forward

The programme for the day revolved around five presentations and two group discussions. See appendix 1 for a copy of the programme, appendix 2 for a list of delegates and appendix 3 for copies of the presentations.

This report is organised according to the main themes that emerged from the presentations and discussion sessions. They are linked to the four objectives outlined above and the overall aim of developing an international and comparative understanding of these issues.

Objective 1: To share information and current perspectives

The presentations allowed for a depth and breadth of information to be shared about best practice and current concerns across a range of countries and settings.

Following the series of international presentations delegates discussed in working groups their main responses. These are summarised as:

- The project conducted by Liz Forbat and Lisa McCann was welcomed, particularly given the priority given to talking directly with people with intellectual disabilities. Participants felt the difficulties in accessing participants was not surprising, though still worrying.

- The epidemiological presentations by Daniel Satgé and Diane Willis raised a number of important differences, for example, in views of prevalence and incidence of women experiencing breast cancer.

- People found it useful to hear a first hand account of being diagnosed with cancer, from Amanda Cresswell. Participants learnt about how the hospital doctors and her GP had communicated with her throughout her diagnosis and treatment.

- It was useful to learn from Linda McEnhill of all the resources and progress made in England. There was a feeling that there was a lot of information which could be centralised and drawn on.

- It would be useful to learn more about supporting people with profound disabilities and people experiencing the more common cancers for this population – such as gastro-intestinal cancers.

Objective two: To identify and explore key issues

Delegate working groups discussed the key issues raised in the presentations.

Existing Practices

- good practice is not shared well enough
- many people are working in isolation
- there is a lack of shared knowledge/experience

Screening

- there is a need to know more about the risks and needs for people with intellectual disability
- raising awareness of screening and if screening is not carried out.

Services

- the communication of a diagnosis of cancer needs to recognise different needs of people with intellectual disabilities
- it seems that little effort is made to assess what level of information people want, need and can absorb
- services for people with intellectual disability are highly variable
- it seems that there is little psychological support available
- it seems that there is little support available for carers and staff
- access to services/the route to diagnosis can be difficult and protracted as the division of care responsibility between services, e.g. Health & Social Work means that it may not be clear where the responsibility for an individual's health may lie.

Information and support

- there is often too little information available, particularly regarding best practice and relevant research
- there is no clear central point of access for information, research, policy and practice
- Carers (statutory and family) are not integrated into the health system or process – Daniel Satgé's ONCODEFI project clearly addresses this.

Objective three: To consider issues for policy, practice and research

In beginning to map out the core issues and ways of addressing them, delegates discussed the implications for policy, practice and research.

Policy

- Define responsibility and guidelines for screening
- Inform policy makers that different social settings will give rise to different needs and provision – someone living at home v. someone in residential care
- Recognise that while inclusion and mainstreaming are to be welcomed this should not be at the expenses of negating or forgetting that certain groups within the overall target population may have very specific and differing needs.
- Recognise that people with intellectual disability would benefit from a greater integration and involvement of everyone involved in their care.
- Support organisations need to communicate with hospitals ready for supporting and preparing a person with intellectual disabilities for death, but there should be a consistent policy in place that equally supports and prepares friends, families and support workers for the death of the person with intellectual disabilities.
- Education for nurses should be increased around intellectual disability as a very small proportion of the training time is spent in intellectual disability settings so to better support people in health care, intellectual disability modules / placements should be increased.
- The new GP contract may result in more people with intellectual disabilities having annual health checks.
- There is a need for further clarity between the boundaries of capacity/duty of care/assault when it comes to screening and health checks for people with intellectual disabilities.

Research

The group felt there is a need for research on

- Cancer incidence statistics in people with intellectual disability
- Best practice in supporting people affected by cancer, carers and staff
- Effective methods for self examination for people with intellectual disability
- Pain management – with particular emphasis on biofeedback/scientific measures
- Screening, and opting out, and its relationship to informed choice
- People with complex needs

Practice

- Of great benefit would be a shared learning space where research could be accessed along with examples of best practice.
- Guidance and methods for raising levels of self examination should be produced – including an option where self examination is not possible.
- Have some mechanism that allows those who know the person well can alert services to small but potentially significant changes in behaviour/functions.
- Raise awareness of cancer in people with intellectual disability; this will facilitate speedier diagnosis
- Encourage greater cooperation between social and health care sectors and include GPs and carers in the equation.
- Awareness of signs and symptoms of cancer (=among all relevant staff and people with intellectual disabilities themselves) is essential in supporting the early diagnosis of people with intellectual disabilities.
- The need for greater recognition of pain and techniques to manage pain were essential.
- Communication between people with intellectual disabilities and health professionals still requires improvement. This necessitates a range of approaches to communication barriers, such as acknowledging the needs and requests of families and support workers.
- There is a need to empower family support workers and the family, and to give quality information to the GP. This could lead to developing a proforma on symptoms to be used in residential care settings.
- There is a need for partnership working – particularly focusing on social work. Liaison nurses could also play a critical role in connecting residential care into primary and secondary care.
- A need to focus on people with complex needs.

Objective four: What might a community of interest look like?

Participants were asked to develop the issues from the previous session and to imagine what a Community of Interest (for cancer in people with intellectual disability) might look like. For example

- who might be involved
- what structures might support these activities
- which organisations might participate and fund

Delegates placed the development of a **Scottish Centre of Excellence** for cancer in people with intellectual disability at the top of the list. The groups teased out the details of the Scottish Centre of Excellence.

The key points were

- The Scottish Centre of Excellence could be real or virtual
- It could be set up in association with the Scottish Consortium for Learning Disabilities (SCLD) or Profound and Multiple Impairment Society (PAMIS).
- It would include people affected by cancer, carers, family members, care providers and policy makers.
- It would be guided by a Steering Group comprising of
  - People affected by cancer (patient/carers/family)
  - NHS, Social Work,GPs
  - Voluntary Organisations
  - A representative from Scottish Government

The remit of any community would be to

- Provide a **central resource** and access point. One method of attaining this would be to develop and maintain a **database** of people interested and working in the field of intellectual disability and cancer would be useful. This would require resources of an administrator to keep it up to date. As a starting point, all of today's delegates would be included. It would be an active resource, where people posted comments and help. It would provide the opportunity to share learning and experience, for example useful paper work such as "health logs"
- Facilitate **communication** between specialist services, including educating families and training health professional staff to communicate effectively with people with intellectual disabilities, in which people with intellectual disabilities should be involved
- to assist in the production of appropriate related **policy**
- **raise awareness** of cancer and needs arising in people with intellectual disabilities
- Carry out **research** into key areas, such as incidence and care needs.
- Include people internationally, to draw on best practice emerging across the globe
- Provide a regular **forum** for people to meet and discuss ideas and experiences
- Facilitate the development of **peer support** for people with intellectual disabilities who have been affected by cancer. This buddy system

would replicate the support group model adopted by the general population and the peer advocacy movement. The aim would be to provide links between people who have had cancer to give each other support.

- In any project or plan focusing on people with intellectual disabilities, it was felt essential to include the full range of **multidisciplinary** colleagues. This must include social workers, as the purchasers and funders of services.
- The community would **support members** to conduct difficult conversations with people – for example, about where they would want to live and die.
- The development of a post of a **liaison nurse** could serve to mainstream cancer support for people with intellectual disabilities. The nurse would work at one of the regional cancer centres, but be linked with a cancer charity (similar to the Northumbria model discussed by Linda McEnhill).

Objective five: To undertake action planning around specific ideas arising from the day‘s discussions

The final task of the day was to identify specific action plans to progress the agenda. Several core areas were discussed and developed.

Pain management

The development of an objective scientific measurement of pain for people with intellectual disabilities was considered ideal to be able to fully assess and manage pain in people with intellectual disabilities affected by cancer. This could also be transferred to other conditions. One idea was the use of biofeedback as an appropriate method of assessment, particularly for individuals with complex intellectual disabilities and where communication skills may be limited. This tool could also be portable so it could be used in people's own or supported living homes. A truly multidisciplinary team would be needed to best advance and develop this work.

Funders for such work would include National Palliative Care Groups – and as the issue is important cross-culturally and cross-country, funding should be sought on a matched basis from each collaborating country.

Improving communication

Action planning for the communication issue focused on the education system and the training available for friends and family, with a number of key questions raised that this sort of work should address:

- Why do the doctors not speak directly to the person with intellectual disabilities?
- What are the barriers for communication?
- What do the doctors and Nurses need to communicate effectively with people with intellectual disabilities?
- What is important for people with intellectual disabilities, and how do we do it?

Further opportunities to share

Delegates were particularly like to see similar events like this being held in the future and would be very keen to attend and share experiences. The *Discovery Group* at Quarriers were mentioned as an action group of people with intellectual disabilities that would be interested in becoming involved in any work that comes out of today, particularly in regards to the communication issues raised today and as part of the Cancer Care Research Centre work.

Baseline studies

Delegates were keen to see a baseline study for areas such as: epidemiology, examples of best practices, available literature and resources

The development of a Centre of Excellence, or community of people interested in this area could be evaluated. The central idea would be that through promoting best practices there is the potential to deliver financial benefits through cost savings.

Concluding Comments

It became clear that many of the attendees felt that they were working in a vacuum, unaware of what others were doing or indeed that they had little understanding of where they fitted within a/the bigger picture.

One of the constant themes of the discussion was the fragmentation or division between health and social care services and sometimes even simply within health care, for example, the division between primary and acute care.

This is not unique to people with intellectual disabilities but given that they may rely on others for information processing and support it was clear that they are sometimes not given the best service.

The next step in progressing the agenda around people with cancer and an intellectual disability is to continue dialogue and debate. Crucially this will be based around the discussions outlined above, and taken forward by a consortium between the Cancer Care Research Centre and the Centre for the Older Person’s Agenda.

Funding to develop these ideas will be sought, and we welcome any further suggestions for taking this agenda forward.

Appendix one: Programme

People with cancer and an intellectual disability: an international issue with local significance

Friday 22nd February 2008

John McIntyre Centre, Pollock Halls, The University of Edinburgh

9.30 Registration and coffee
10.00 Chaired by Alan Gow, Macmillan Cancer Support

Speakers:
Liz Forbat and Lisa McCann, Cancer Care Research Centre, University of Stirling
Amanda Cresswell, Actor with Strathcona Theatre company
Diane Willis, Napier University, Edinburgh
Daniel Satgé, Centre Hospitalier, Tulle, France
Linda McEnhill (on behalf of Irene Tuffrey-Wijne), UCL, London

11.30 Coffee break
11.45 Working groups and feedback
1.15 Lunch
2.00 Action planning
3.15 Coffee break
3.30 Sharing commitment
4.00 Close

Appendix two: Attendees

People with Cancer and an intellectual disability: an internationa

John McIntyre Centre, The University of Edinburg

22nd February, 2008

Delegate Listing

Name	Job Title	Organisation
Alan Gow	Development Coordinator Scotland	Macmillan Cancer Support
Ms Valerie Barclay	Charge Nurse	NHS Ayrshire & Arran
Dr Dorothy Margaret Bell	Consultant Clinical Psychologist	NHS
Ms Yvonne Chapple	Learning Disability Liaison Nurse	Learning Disability Service
Amanda Cresswell	Actor	Strathcona Theatre Company
Mr John Davidson		NHS Lothian
Dr Liz Forbat	Senior Research Fellow	University of Stirling
Mrs Hilda Griffin	Community Learning Disability Nurse	NHS
Mrs Irene Hattie	Projects Manager	Quarriers
Mrs Jean Howieson	Acute Liaison Nurse Practioner	NHS Lanarkshire
Lisa McCann	Research Assistant	University of Stirling
Ms Linda McEnhill	Widening Access Project Manager	National Network for Palliative Care of Pe with Learning Disabilities
Ms Sandra Morrison	Learning Disability Liaison Nurse	NHS Fife
Mrs Lynda Murdach	Senior Nurse Acute Liaison - Learning Disability	NHS Tayside
Mrs Lindsey Orr	LD Acute Liaison Nurse	NHS Forth Valley
Mrs Eileen Parkhill	Project Manager	Quarriers
Ms Linda Radcliffe	Health Advocate	West Dunbartonshire Learning Disability Service
Dr Raghu Raghavan	Reader	Northumbria University
Mrs Gill Reid	Depute Director	FAIR
Daniel Satgé		Centre Hospitalier
Carol Shields		NHS Lothian
Ms Tracey Sim	Volunteer Development Manager	Cornerstone Community Care
Miss Mhairi Simpson	Nurse Consultant Cancer Care	NHS Lanarkshire
Stine Skorpen	Project Manager	Ageing and Health, Norwegian Centre for Research
Scott Taylor	Liaison Nurse Learning Disabilities	NHS Lothian
Mrs Sara Ann Turner	Team Leader	Quarriers
Britt-Evy Westergard		UAU
Dr Irene Tuffrey-Wijne	Research Fellow	UCL, London
Mrs Fiona Wilkie	Community Nurse	NHS Lothian
Miss Elizabeth Jane Wilkinson	Consultant Clinical Psychologist	NHS
Heather Wilkinson	Co-Director CRFR	The University of Edinburgh
Allan Williamson	Regional Manager	Key Housing
Diane Willis	Cancer Nursing Research Fellow	Napier University, Edinburgh
Miss Ruth Young	Assistant Psychologist	NHS Lothian