

**Macmillan Cancer Support and Yorkshire Cancer  
Network**

**Researching Inequalities in Cancer  
Services -  
Learning Disabilities Work Stream**

**Easy-Read End of Project Report  
Recommendations**

**December 2012**

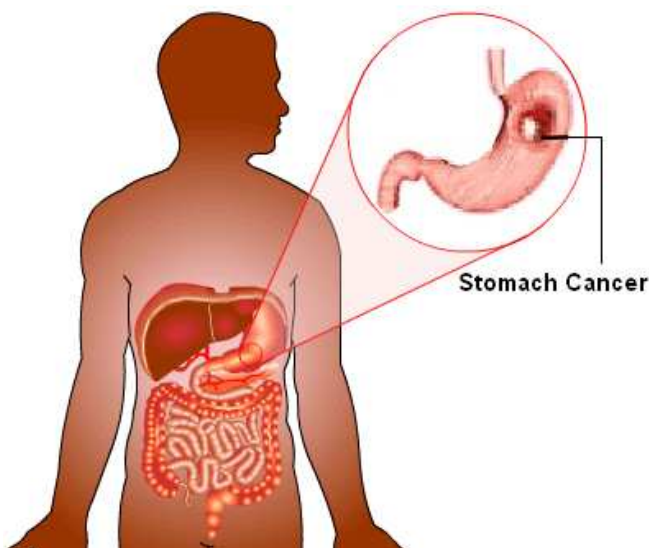
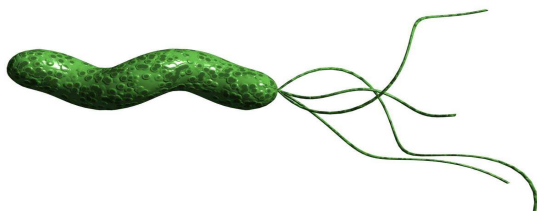
**Compiled by  
Francesca Evans**



## **Recommendation 1**

**All hospitals within the Yorkshire Cancer Network area should set up a system which tells staff when people with learning disabilities go into the hospital.**

**It should also record information about their visit so that more can be known about their health.**



## **Recommendation 2**

**All staff who work with people with learning disabilities should receive training on a germ which is linked to some cancers.**

**They should also be told about ways in which infection by this germ can be stopped.**

**This germ is called helicobacter pylori.**



### **Recommendation 3**

**The Government should continue to pay for annual health checks for people with learning disabilities.**

**The Government should also collect information about how good these checks are at finding new cases of illness so we can see how useful the health checks are.**



### **Recommendation 4**

**All areas within the Yorkshire Cancer Network should work towards making sure at least 7 out of ten adults with learning disabilities get health checks.**



### **Recommendation 5**

**Local cancer screening teams across the Yorkshire Cancer Network area should talk to each other to share good ways of working.**

**They should make sure that all screening staff are aware of the needs of people with learning disabilities.**





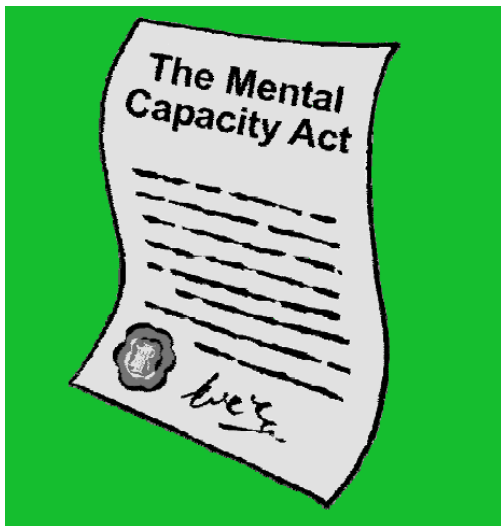
## Recommendation 6

No one should be taken off screening lists if it is decided that they do not have capacity to make this decision for themselves unless a Best Interests Meeting has been held.

## Recommendation 7

All staff who work with people with learning disabilities should be given training to make sure they are aware of the Mental Capacity Act and how to use it.

Staff awareness of Independent Mental Capacity Advocates, how to contact them and what they do should also be improved.



## Recommendation 8

Information sessions about cancer, cancer screening and the early signs and symptoms to look out for should be run for people with learning disabilities, their families and carers across the Yorkshire Cancer Network area.





## Recommendation 9

National guidelines should be produced for health and social care staff about how to support people with learning disabilities to check themselves for signs of cancer.

This should include information on what to do for people who are unable to do self-checks for themselves.

People with learning disabilities should be offered information including invites to awareness raising sessions, about self-checking for signs of cancer by their local health teams.



## Recommendation 10

Patients should be able to exit appointments where they are told they have got cancer into a separate area from the general waiting area.



## Recommendation 11

**Training in learning disabilities should be offered as part of courses teaching people to be a doctor or nurse.**

**People with learning disabilities and their carers should be involved in developing and delivering this training.**

## Recommendation 12

**Health care staff who have already completed their training should attend awareness sessions about people with learning disabilities.**

**This training should include suggestions about what they can do to make sure that people with learning disabilities have the same access to health care as anyone else.**

**Doctor's surgeries, health centres, hospitals and hospices should sign up to Mencap's Getting it right charter.**

### Getting it right charter

See the person, not the disability

All people with a learning disability have an equal right to healthcare.  
All healthcare professionals have a duty to make reasonable adjustments to the treatment they provide to people with a learning disability.  
All healthcare professionals should provide a high standard of care and treatment and value the lives of people with a learning disability.  
By signing this charter, we pledge to:

- ✓ make sure that hospital passports are available and used
- ✓ make sure that all our staff understand and apply the principles of mental capacity laws
- ✓ appoint a learning disability liaison nurse in our hospital(s)
- ✓ make sure every eligible person with a learning disability can have an annual health check
- ✓ provide ongoing learning disability awareness training for all staff
- ✓ listen to, respect and involve families and carers
- ✓ provide practical support and information to families and carers
- ✓ provide information that is accessible for people with a learning disability
- ✓ display the Getting it right principles for everyone to see.

For guidance on implementing this pledge, please visit [www.mencap.org.uk/gettingitright](http://www.mencap.org.uk/gettingitright)



### **Recommendation 13**

**Hospitals should make sure that all patients who come to hospital for cancer treatment are given the contact details of someone called a key worker who they can contact to ask questions.**



### **Recommendation 14**

**All hospitals in the Yorkshire Cancer Network area should have an Acute Hospital Liaison Nurse in post to make sure reasonable adjustments are made so that equal access, information and treatment are given to people with learning disabilities.**



### **Recommendation 15**

**Information on benefits, complementary therapies and support groups should be given to all cancer patients in the information pack they are given at their first appointment.**



### **Recommendation 16**

**All patients with learning disabilities should be offered counselling, preferably with counsellors from Specialist Learning Disability Health Teams.**



### **Recommendation 17**

**All patients with learning disabilities should be offered breast reconstruction following a mastectomy to make sure they are treated in the same way as any other patient.**





## Recommendation 18

Hospitals should find ways to make the end of treatment experience of patients better so that they do not feel so abandoned.



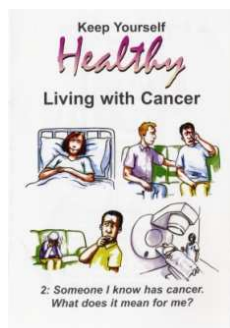
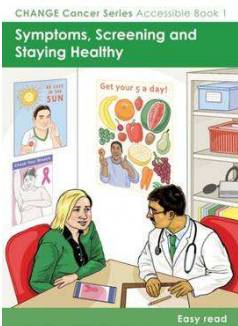
## Recommendation 19

Providers to ensure the appropriate use of tools available to help communication with people with a learning disability such as Distress Awareness Tool, or DisDAT, Health Passports Anticipatory Care Calendar and others

## Recommendation 20

Some accessible information and details of where to find more should be available everywhere that offers medical treatment or advice.

Health staff should know what is available and have copies to give to patients at appointments or be able to tell them where to get them.





## **Recommendation 21**

**An Information Prescription or list of accessible information about cancer should be written for people with learning disabilities who have cancer.**



## **Recommendation 22**

**Places which offer cancer services should make sure they are accessible to people with learning disabilities.**

**They should also make sure they make a plan of action about how they can make some of the recommendations in this report happen in their area.**

**If this happens it will help to improve the experience of cancer services for people with learning disabilities.**