

# Support Pack for Tutors



## Health as a Topic for Adult Literacy Programmes

Self Management Programme  
Long Term Conditions Unit  
Scottish Government  
St Andrews House, Regent Road  
Edinburgh EH1 3DG

CLAN Health and Literacy Project  
Pennywell Resource Centre  
Pennywell Road  
Edinburgh  
EH4 4PJ

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# Using health as topic for adult literacy programmes: investigating the impact of poor literacy on finding local support to manage long term conditions.

## Introduction to pack

This pack is an outcome of the Health Literacy workstream of ALISS (Access to Local Information to Support Self Management) a Scottish Government project. (see <http://www.aliss.scot.nhs.uk>). This workstream was called "My Health – Finding Local Support" which will be referred to in this pack as "My Health". The project collaborated with 2 groups of adult learners in Edinburgh with an aim of learning more about how they accessed local health support and is designed for adult literacy learners to use as a class topic.

Health is a rich topic to explore in adult literacy groups as some adult literacy learners are interested in finding out about health conditions which affect them or their families and some may have difficulties understanding information about health and communicating with health services.

Health topics can be the foundation of useful activities for literacy learners and can be woven into learning in a variety of ways such as reading, writing and comprehension activities or as mini projects or local investigations.

As people and carers are encouraged to play a more active role in their care, and share decisions about treatments, it is important that they properly understand health services and medical conditions. To do this effectively they need to be aware of local networks and activities that offer support to keep them healthy.

Learning more about long term conditions and sources of support, proved to be a fruitful class activity. It offered opportunities to share experiences and ideas, have animated group discussions and to research aspects of personal health as part of individual learning plans.

The project was sponsored by the Self Management Programme, Long Term Conditions Unit of Scottish Government in collaboration with the Edinburgh City Literacy and Numeracy (CLAN) Health and Literacy Project and supported by the Long Term Conditions Alliance Scotland (LTCAS).

## **Aims of 'My health: finding local support'**

- To discuss what people consider to be long term conditions
- To find out more about particular long term conditions which affect learners and their families
- To learn where and how people obtain health information
- Investigate local sources of support and share findings with the group
- To learn what local support people want
- To encourage learners' confidence to discuss health issues and access local facilities
- Identify barriers to accessing local support and ways to overcome them
- To record personal benefits of the exercise to learners

# Tutor Pack

## Pre-course preparation

The experiences of health for the groups will be varied, so allow the project a few weeks so that learners have time to develop their investigation and act on useful information they find. My Health arranged class sessions with each group. Between the second and third session, learners explored their own community to record their experience of obtaining information. The format is described in detail in this pack.

## Confidentiality and Disclosure

- When discussing health in a group it is vital that tutors set clear boundaries about confidentiality at the outset. Personal information must not be repeated outside the group. Tutors must prepare for learners to disclose personal details about their health and ensure that participants are not vulnerable or uncomfortable. It is advisable to formalise consent to participate and an example consent form is included in this pack.
- Choose a comfortable venue where you will not be disturbed and discussions cannot be overheard. People must feel secure and relaxed. If possible have an additional room if recording people's stories or having one to one discussions. Provide refreshments.

## Recruit someone with a background in health to support the group

- Medical knowledge and awareness of local services will be a useful addition to the group. Health visitors, practice or district nurses could be invited to participate as part of community development work.
- There may be existing community health projects or health related voluntary agencies in your area who will agree to participate.

## Do a bit of pre-course investigation of the local area yourself

- Find out about health, social and community services in the area so that you can inform discussions. It is likely that learners will find additional sources of information in the course of their investigations.
- Gather a selection of health information leaflets and posters on a range of long term conditions. You can get these from health improvement or health education departments, doctors' surgeries or libraries. Use these to initiate discussions and find out how useful people find them.

## Organise equipment to record individual stories

- Disposable cameras, video cameras and mobile phones are useful for recording experiences. (My Health used simple MP3 players for recording audio but the model was too small, with fiddly controls. Most learners used their mobile phones). Audio files were downloaded from mp3 and phones for editing.
- Many people have mobile phones which take photographs and record sound. Discuss preferences with learners and ensure you can download and re-present the variety of material that may be collected. It is advisable to rehearse this in advance.

# Description of Sessions

A short description of the sessions can be found in the Aliss Health Literacy Work-stream Report

My health: finding local support Session 1	
<p>1. Discussion about long term conditions.</p> <ul style="list-style-type: none"><li>• What are they?</li><li>• Which ones are of interest to you and why?</li></ul>	<p>Possible outcomes</p> <ul style="list-style-type: none"><li>• A list of health conditions known to the group.</li><li>• Agreement on a definition of what a long term condition is. E.g. any health condition which stays with you over a long period of time, or for life.</li><li>• Deciding which conditions the group are interested in finding out more about.</li><li>• Some general understanding of what people know about these conditions so far.</li></ul>
<p>This discussion may take up to two hours depending on number of participants, their interest and confidence in speaking.</p>	

<p><b>2. Living with a long term condition.</b></p> <ul style="list-style-type: none"> <li>• What do you think of as support? Any recent experiences?</li> <li>• Who do you ask?</li> <li>• Where do you go?</li> <li>• Who do you think of?</li> <li>• Where do you start?</li> </ul>	<p><b>Possible outcomes</b></p> <ul style="list-style-type: none"> <li>• This discussion allows an opportunity to focus on sources of support to live well with a long term condition and the group's experiences.</li> <li>• Create lists of individuals or organisations that people have found supportive.</li> <li>• Create a list of barriers people have come up against in finding satisfactory support.</li> <li>• Create a list of local sources of support that group members have either used or heard about.</li> </ul>
<p>These discussions will stimulate sharing of information and some ideas of the directions that your project might go in.</p>	
<p><b>3. Review examples of health information leaflets and posters.</b></p> <p>Set up a mock waiting room style display and ask learners to select things they find interesting and things they might avoid. They can do this individually or in pairs.</p> <ul style="list-style-type: none"> <li>• What sort of information attracts you? What helps?</li> <li>• What puts you off?</li> <li>• How useful would you find this information?</li> <li>• Does this information help you to find health support?</li> </ul> <p>Ask people to report their findings back to the group and ask their opinions.</p>	<p><b>Possible outcomes</b></p> <ul style="list-style-type: none"> <li>• Learners' responses will give an insight into how accessible the language and images used in the materials are and how they value this type of information. Is it the sort of thing that they actively seek out and use in their everyday lives?</li> </ul> <p>Everyone might not agree on what they like and dislike about the information on display. This can be interesting to unpick and to reinforce the fact that we might be looking for different things.</p>

#### 4. For next time.

- Think about where you and your family get support and how you found out about it.
- If you have any health booklets or leaflets at home bring them along next time and tell us what you think of them.

#### Possible outcomes

- Learners have the chance to think about what they discussed in session 1 and how it relates to their lives.
- They may contribute ideas formed during the week
- They may share useful information which will reinforce confidence and skills in managing their own health.
- They may share information or leaflets with the group that they have been unable to understand. This provides a rich learning experience.

**My health: finding local support Session 2**

<p><b>1. Feedback from last time:</b></p> <ul style="list-style-type: none"><li>• Comments on personal interest in long term conditions.</li><li>• Information people have brought along to show the group.</li></ul>	<p><b>Possible outcomes</b></p> <ul style="list-style-type: none"><li>• Focuses attention on the long term conditions of most interest to the group.</li><li>• Gives people the opportunity to talk about their experiences of using health information to support conditions affecting them or their families.</li></ul>
<p><b>2. Show DVD of accessing local information (see Patience Story: <a href="http://vimeo.com/8717594">http://vimeo.com/8717594</a> )</b></p>	<p><b>Possible outcomes</b></p> <ul style="list-style-type: none"><li>• Discuss the experience – is it familiar? Group discussion – is story shown similar to their experience?</li><li>• Look back at sources of support you discussed in Session 1. Would the person in film be supported in your area?</li></ul>
<p><b>3. Learners' stories. Where could they find support in your area?</b></p>	

#### 4. Preparing for learner's investigations in their community.

- Group discussion on local amenities; health services, voluntary organisations, social and community services.
- Input from local health worker. This could include examples of things local people do to support their long term conditions.
- Learners should now decide what they are going to investigate. You can do this individually or in small groups. If possible have a facilitator with each group to guide people on the practicalities of carrying out their investigation.
- Help learners to make a plan about where they will go and who you will approach.
- Decide how they will record their findings. Record sheets, photographs, MP3 recorders, mobile phones can all be useful. If necessary practise recording so that they get used to the sound of their recorded voice.
- Provide tutor contact details so that learners can call if they need support or reassurance whilst carrying out their investigation.

#### Possible outcomes

- Use the lists you created in Activity 2 in Session 1 when you discussed sources of support. Learners may have some to add since last time.
- A health worker may be able to make a few more suggestions and may advise on different types of support.
- Throughout the discussion process, learners may change their minds about what they want to investigate as their interest develops. At this stage they should now fix on a particular condition or topic so that they can be focused.
- Whilst learners will get the most out of their experience by deciding what to investigate and how to go about it, facilitators do have some responsibility to make sure that their plans are manageable in the timeframe.
- Some learners are confident about using technology and recording notes is a quick and easy way for them to record their progress. Others might be surprised at how easy it is to use recording equipment, once they are shown how. However some might prefer written notes and it is important that time is taken to ensure everyone feels comfortable with what they are doing so that no one feels excluded from the task.

#### 5. Carry out your investigation

**My Health: finding local support Session 3**

<p><b>1. Report back findings.</b></p> <p>Learners finding feedback on their experience of finding local health information. You may find this easier to do 1:1 and be able to respond to each learner's experience. Reporting back to the group can come later.</p>	<p><b>Possible outcomes</b></p> <p>Tutors and facilitators need to be responsive to the learners' experiences. This is particularly important if things didn't go entirely to plan as you may need to offer advice and encouragement on what to do next.</p>
<p><b>2. Download photos and recordings.</b> Collect written record sheets (see Appendix A)</p>	<p><b>Possible outcomes</b></p> <ul style="list-style-type: none"> <li>• Tutors can review learner's record before next session so that they are prepared to support them when making decisions on how to use their findings.</li> <li>• Tutors must take into account time needed to listen to recordings. Assisting learners to edit their notes may be a separate learning activity.</li> <li>• Learners may store photographs to illustrate their reports at a future date.</li> </ul>
<p><b>3. Any follow up research required? Need any additional information?</b></p>	<p><b>Possible outcomes</b></p> <ul style="list-style-type: none"> <li>• Again tutors need to be responsive. If learners feel that they want to do more, they may require additional guidance, reassurance and encouragement.</li> <li>• Alternatively, learners may have found sufficient information about support and want to act on it. This may also require guidance.</li> </ul>

**My health: finding local support Session 4**

**Feedback to the group**

Each learner informs the group about how they got on with their investigation, outcomes, high points, low points, challenges and what they plan to do with what they have found.

**Possible outcomes**

Learners can learn a great deal from each other and they may have a lot to share from their experiences.

**Follow up and possible sources of support**

- One of the aims of this project is to find local support for long term conditions. If learners find a useful source they can now follow it up.
- This might involve additional literacy work in locating venues, reading timetables or making telephone calls.
- Learners can keep a diary of their progress and if their expectations of the support are met.

**Possible outcomes**

Individual learners may feel more confident in seeking support for their long term conditions. They may want to continue to use their literacy group to carry out research or to test new ideas.

**Use information to form a presentation in a style of learners' choice.**

Illustrated reports, picture stories, blogs or diaries could be created with the information collected in the course of this project.

**Possible outcomes**

- As learners collect material which is of relevance to them, they may be more inspired to write about it.
- Outcomes from this project could be used in SQA modules.
- The process of carrying out this project may open up many other health related issues which learners would like to investigate and so their learning journey has just begun.

## Further Information

You might find some of these links useful;

Long Term Conditions Alliance Scotland

<http://www.ltcas.org.uk/>

Managed Knowledge Network for self management and rehabilitation

<http://www.enablinghealth.scot.nhs.uk/home.aspx?referer=AAS&un=nouername>

Web pages for information / resources on long term conditions

<http://ltcscotland.wik.is/>

Co Creating Health, Health Foundation - Supports UK organisations to embed self-management in processes

[http://www.health.org.uk/current\\_wor...ng\\_health.html](http://www.health.org.uk/current_wor...ng_health.html)

Long Term Conditions Collaborative

<http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/Delivery-Improvement/1835/210369>

### Adult Literacy and Health Literacy

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Learning Teaching Scotland

<http://www.ltscotland.org.uk/literacyandnumeracy/>

Adult Literacy Online (includes resources)

<http://www.aloscotland.com/alo/sitesearchresults.htm>

National Literacy Trust

<http://www.literacytrust.org.uk/policy/scotland.html>

American Medical Association Foundation Health Literacy Initiative

<http://www.ama-assn.org/ama/pub/category/8115.html>

Scottish Government adult literacy and numeracy campaign website

[www.thebigplus.com](http://www.thebigplus.com)

National Patient Safety Foundation – Ask Me Three

[www.npsf.org/askme3](http://www.npsf.org/askme3)

Improving communication

[www.plainlanguage.gov/](http://www.plainlanguage.gov/)

Quick guide to health literacy (includes resources)

[www.health.gov/communication/literacy/quickguide/healthinfo.htm](http://www.health.gov/communication/literacy/quickguide/healthinfo.htm)

Patient Information Forum - UK organisation for people who work in consumer health information, in whatever role – dedicated to better communication for better health  
<http://www.pifonline.org.uk/themes/health-literacy/>

## **Patient experience**

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Better Together – Scotland Patient's Experience Programme

[http://www.bettertogetherscotland.com/bettertogetherscotland/CCC\\_FirstPage.jsp](http://www.bettertogetherscotland.com/bettertogetherscotland/CCC_FirstPage.jsp)

UK website for people to share experience and contribute to blogs

<http://www.patientopinion.org.uk/>

Patients like me – sharing experience and helping research / clinicians

<http://www.patientslikeme.com/>

NHS Choices bloggers – people writing about day-to-day living with their conditions, online

<http://talk.nhs.uk/>

Health Talk – a research project-based collection of videos of personal experiences of a wide variety of conditions and illnesses

<http://www.healthtalkonline.org/>

## **Patient Safety**

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Scottish Patient Safety Programme

<http://www.patientsafetyalliance.scot.nhs.uk/>

## **Information for public and staff**

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Long Term Conditions Alliance Scotland

<http://www.ltcas.org.uk/>

NHS24

<http://www.nhs24.com/content/>

Elibrary – Health Education Scotland

<http://www.elib.scot.nhs.uk/portal/elib/pages/index.aspx?referer=AAS&un=nousername>

Scotland's Health on the Web - SHOW

<http://www.show.scot.nhs.uk>

Information Services Division Scotland (ISD)

[http://www.isdscotland.org/isd/CCC\\_FirstPage.jsp](http://www.isdscotland.org/isd/CCC_FirstPage.jsp)

## **ALISS Project Blog**

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<http://www.aliss.scot.nhs.uk>

## Background reading

DeWalt DA, Beckman ND, Sheridan S, Lahr KN, Pignone MP 2004. Literacy and Health Outcomes. A Systematic review of the Literature. *Journal of Internal Medicine* 19: 1228-1239; <http://www3.interscience.wiley.com/cgi-bin/fulltext/118783767/PDFSTART>

Ad Hoc Committee on Health Literacy (1999) 'Health literacy: report of the Council on Scientific Affairs, American Medical Association'. *JAMA*, 281 (6): 552-557.

Institute of Medicine (2004) *Health Literacy: a prescription* Washington DC: The National Academies Press.

Sihota, S. & Lennard, L. (2004) *Health literacy: being able to make the most of health*. London: National Consumer Council.

Patient Focussed Interventions- A Review of the Evidence, Coulter; Ellins, Picker Institute 2006

US Department of Health and Human Services, "Healthy People 2010, Understanding and Improving Health", November 2000

Closing the Loop, Physician Communication with Diabetic Patients Who Have Low Health Literacy, Dean Schillinger, et al, *Archives of Internal Medicine*, Vol 163 (1) 83 – 90, Jan 2003

The Scottish School of Primary Care; [http://www.sspc.ac.uk/living\\_well.htm](http://www.sspc.ac.uk/living_well.htm)  
[www.health.gov/communication/literacy/quickguide/healthinfo.htm](http://www.health.gov/communication/literacy/quickguide/healthinfo.htm)

## Health and Literacy Projects in Scotland

### Edinburgh:

Elspeth Hosie  
CLAN Health and Literacy Project  
Pennywell Resource Centre  
Pennywell Road  
Edinburgh  
EH4 4PJ

Tel 0131 537 4230  
e-mail: [elspeth@clanedinburgh.org](mailto:elspeth@clanedinburgh.org)

### Glasgow:

Catriona Carson,  
Senior Development Officer for Literacies and Health,

Tel: 0141 232 0163  
e-mail: [catriona.carson@gghb.scot.nhs.uk](mailto:catriona.carson@gghb.scot.nhs.uk)

### Aberdeen

Suzanne MacAulay  
Healthwise Aberdeen  
Torry Learning House  
12A Balnagask Road  
Aberdeen  
AB11 8HX

Tel: 01224 896156  
E-Mail [info@healthwise-aberdeen.com](mailto:info@healthwise-aberdeen.com)

Appendix A: Record Sheet

**My Health – Finding Local Information**

**How did you get on with .....**

	YES	NO	COMMENTS
Welcoming			
Friendly			
Helpful			
Had information I needed			
I understood the information I was given			
Gave me an idea for somewhere else to try (e.g. - the web/my GP etc)			

## My Health – Finding Local Information

How did you get on with ... **the local library** ?

	YES	NO	COMMENTS
Welcoming	<b>X</b>		
Friendly	<b>X</b>		
Helpful		<b>X</b>	<b>They told me straight away that I was in the wrong place</b>
Had information I needed		<b>X</b>	<b>They did not have any information for me</b>
I understood the information I was given			
Gave me an idea for somewhere else to try (e.g. - the web/my GP etc)	<b>X</b>		<b>They suggested I try the web to find local support</b>