

## UNIT 3: WHAT'S IN A WORD?

## TEACHERS' NOTES UNIT 3

### WHAT'S IN A WORD?

#### OBJECTIVES

To explore the labels we use to describe ourselves and others.

To encourage students to reflect on the theory that it is society which disables people by failing to meet their needs.

#### SUGGESTED AGE RANGE

14-16 year olds.

#### CURRICULUM LINKS

For use in PSE, English, Social Studies, Equal Opportunities, Modern Studies (Scottish Certificate of Education).

#### SUMMARY OF CONTENT

In Part 1, students explore what they mean when they say someone is 'healthy', 'unlucky', 'active', 'special' etc. In an interview with Joanne, a young woman who sometimes uses a wheelchair because she has Osteogenesis Imperfecta (brittle bones), we see how a person's life and expectations can be affected by the labels which society gives them. Why should people who are labelled 'disabled' not have the same opportunities as everyone else? In Part 2, students explore what is needed to make sure that everyone, including Joanne, Janet and Emma (two young women with impaired hearing and vision due to Usher Syndrome), can fully participate in ordinary, everyday activities.

#### TEACHERS PLEASE NOTE

It is important to be aware of the fact that some students in the class may themselves have a genetic condition, or be a carrier, or have a relative who is affected. Sensitivity is required to avoid putting such students under stress.

You might like to also consider using Unit 4 — Hitting back? with your students. Unit 4 looks at bullying and discrimination and asks students to come up with positive verbal responses to people who label or stereotype in a hurtful way.

## TEACHERS' NOTES UNIT 3: PART 1

### MATERIALS NEEDED

For Part 1, photocopies of the following: Activity Sheet 1 plus Genetic Condition Card: Osteogenesis Imperfecta (one copy of each per student).

### WHAT YOU DO

Explain that you are going to start the lesson by thinking about words we sometimes use to describe or 'label' people and about what it feels like when these words don't fit or stop us from seeing the real people behind the labels.

Begin by writing the following adjectives randomly on a large piece of paper or on the board:

**healthy**  
**different**  
**disabled**  
**active**  
**unlucky**  
**unique**  
**special.**

Ask students to write down all the words on a piece of paper and to tick any which they think describe them. Stress that this is a private activity — they will not have to show anyone which words they have ticked.

Then ask students to pair up with the person sitting next to them and to finish the following sentences together:

A 'healthy' person is someone who...

A 'disabled' person is someone who...

A 'special' person is someone who...

Ask different pairs to read out their contributions and see if the class can agree on a definition. What about combinations? Is it possible to be:

...'active' AND 'disabled'?

...'different' AND 'happy'?

...'healthy' AND 'unlucky'?

Explain that we often use 'labels' to describe people. This can happen in families — 'Of course so and so is the clever/talented/good looking one', or in casual conversation — 'You know who I mean — the fat one with greasy hair!'. We may not even notice that we're doing it. But these labels can have a very damaging effect. They can take away a person's confidence and even affect their basic rights.

### Give each student a copy of Activity Sheet 1 — Joanne's story plus the Osteogenesis Imperfecta (OI) Genetic Condition Card

Ask if any students have heard of/ are familiar with OI (N.B. OI is also known as 'brittle bones'. We have not used the term 'brittle bones' here because of potential confusion with Osteoporosis). Then ask students to get into groups of three so they can read the Genetic Condition Card and Joanne's story together before working through the questions in their groups. [With mixed ability students, you might like to read through the Genetic Condition Card and Joanne's story as a whole class and work through the questions together.] Set a time limit for the activity.

As a whole class, go through the Questions for Discussion together (you can use the notes for Teachers on Activity Sheet 1 to help you).

## TEACHERS' NOTES UNIT 3: PART 1

### QUESTION FOR DISCUSSION : Joanne's Story

Which of the following words would you use to describe Joanne?

...healthy...different ...disabled ...active ...unlucky ...happy ...unique ...special?

Be prepared to explain why/why not to the rest of the class

### COMMENTARY

There are no right or wrong answers to this question. Much depends on how students define words such as 'healthy', 'active' and 'disabled'. Joanne's own answers are printed below.

#### HEALTHY:

'To an extent, yeah. My mind's healthy and I'm totally with it. I've been having a lot of back problems lately so I'm quite run down at the moment and I've been picking up a few colds here and there. I've got a chest infection right now but in between times I feel quite fit.'

#### DIFFERENT:

Not normally, but in some situations I do because of other people's attitudes. It's the looks mostly and the way people stare. There've been some funny times though. I was in the town centre once in my wheelchair with Rachel on my knee and this woman was gawping so hard that she fell head over heels over a massive cast-iron litter bin and landed on her backside. People around her were just laughing at her. But I don't feel different in myself apart from the fact that I use wheels.'

#### DISABLED:

'No. I don't actually feel disabled. It's things like access and people's comments and stares which make me feel disabled.'

#### ACTIVE:

'Yeah I think I'm quite active considering my mobility. And of course there's Rachel to keep me busy. Even with both legs and an arm in plaster she still tries to get up the stairs!'

#### UNLUCKY:

'No. I don't think I'm unlucky. I was born with the condition so I don't know any different. Maybe if I was paralysed and it had happened to me later on I might feel unlucky, but I've lived with OI all my life.' HAPPY: 'I think I am actually. Everybody keeps saying 'how can you be so happy when all this is going on?' but I mean you have to. I think if you sat and moped around all day you'd just turn into a complete vegetable and you'd never do anything. So I think you have to be happy really. Most of my down moments were when I was about 13 or 14. I was going through puberty, my hormones were doing whatever they wanted and I wanted to be out and about like my brother and go to parties or whatever. That's when I felt like committing suicide.'

## TEACHERS' NOTES UNIT 3: PART 1

### UNIQUE:

'No, I don't think I'm unique. I think every disabled person must go through most of what I go through, and all the people with OI at some point or other have gone through the same stuff as me.'

SPECIAL: 'Yeah, I think I'm special. I mean having Rachel... I was always told I couldn't have kids so I feel special in that way, and sharing all her growing up makes me feel special too. And I cheer people up a lot.'

### QUESTION FOR DISCUSSION

In what ways have other people's attitudes towards Joanne affected her education, social life and expectations? Is this fair/right?

### COMMENTARY

In her interview, Joanne mentions a number of ways in which her life has been affected by other people's attitudes. For example:

**EDUCATION:** on her first day at a new school, she was thrown against a wall to see if her bones would break. They did. The educational psychologist then told her that she could not be educated within the mainstream system. At her special school, the work was, in her own words, 'degrading'. Attempts at further education were hampered by lack of funds and problems with physical access to college buildings.

**SOCIAL LIFE:** Joanne says she spent a lot of time in and watching TV when she was younger while her brother was out partying. Now she has few friends apart from the carers.

her yoga course because social services withdrew funding for a carer to accompany her. According to Joanne, the local day centre is full of severely disabled people. Ask students to think about how people make friends. Is it easy to make friends if you have restricted mobility, no income and are a single parent?

**EXPECTATIONS:** Joanne was always told she would never have children. As soon as her pregnancy was confirmed, she was expected to have a termination. Very little was expected of her at school or at college where she was not intellectually stimulated or challenged. If she wants a holiday, she is expected to go with other disabled people. When she is using her wheelchair, some people assume that her reduced mobility means that she cannot think or talk. If Rachel has a suspected fracture and Joanne walks into casualty with her (rather than using her wheelchair), some junior doctors suspect her of abuse

Is this fair/right? Should a person with a genetic condition expect to be a second-class citizen? Why should Joanne not have equal opportunities?

### QUESTION FOR DISCUSSION

- How do the words we use to describe people reflect our attitudes towards them?

### COMMENTARY

The words we use to describe people can tell us something about our own attitudes and feelings too. Ask students how they would feel if someone told them they were 'special'. Would they be pleased? If someone told them they were 'different', would they feel they were being complimented or criticised, or both?

## TEACHERS' NOTES UNIT 3: PART 1

### COMMENTARY

Many people who are 'disabled' argue that it is society which disables them. They say that if all buildings and transport were fully accessible and everyone had equal educational and job opportunities, they would not be 'disabled' because they would be on equal terms with everyone and have the same choices. This idea is explored more fully in Activity Sheet 2.

## TEACHERS' NOTES UNIT 3: PART 2

### MATERIALS NEEDED

Photocopies of the following:

Activity Sheet 2 (one copy per pair of students). Activities Sheet on page 40 — one cut-up slip with two activities on it per pair of students.

Task Sheet: Joanne or Task Sheet: Janet and Emma (one copy per pair of students).

*[N.B. When deciding which Task Sheet to give to your students, it might help to know that Task Sheet: Janet and Emma requires further reading; Task Sheet: Joanne does not.]*

**Pairs of students working on Task Sheet: Janet and Emma will also need:**

**one copy of Genetic Condition Card: Usher Syndrome a photocopy of the relevant section from the Information about Janet and Emma on pages 41 - 45.**

### WHAT YOU DO

Ask students to think about the word 'disabled'. It is true that Joanne needs to use a wheelchair some of the time but she does not see herself as 'disabled'. If schools, colleges and the community took the needs of disabled people into account, would they still be 'disabled'?

Explain that as well as thinking about Joanne, you are going to focus on two other young women (Janet and Emma) who both have Usher syndrome. This is a genetic condition which affects hearing and vision. A person with Usher Syndrome is born deaf and develops RP (Retinitis Pigmentosa), a condition which affects the eyes and leads to night-blindness and loss of side vision (although reading vision can be good for many years).

You are going to ask students to explore whether Joanne, Janet and Emma are 'disabled' because they have a genetic condition or because society fails to meet their needs.

Ask students to work in pairs. Give each pair Activity Sheet 2, a cut-up slip with two activities on it from the Activities Sheet on page 40 and the Task Sheet (either Joanne or Janet and Emma) which you have selected for them. Make sure you give students working on Task Sheet: Janet and Emma the extra information they need

*Read through Activity Sheet 2 together and go through the example on the sheet with students to make sure they have time in each pair to fill in their own Task Sheet for the two activities they have been given.*

## TEACHERS' NOTES UNIT 3: PART 2

Bring the students back together as a whole class to process the activity (you can use the Notes for Teachers on Activity Sheet 2 to help you).

Make sure you have read through Activity Sheet 2 and are familiar with the information on Genetic Condition Cards: Osteogenesis Imperfecta (OI) and Usher Syndrome.

Activity Sheet 2 is designed to help students explore in a practical way the idea that it is society which 'disables' people by denying them basic rights and failing to meet their needs.

When you process the activity with students, it is helpful to start with what they have written in the 'What do we all need in order to do this activity' column. For example, everyone who wants to go shopping will need some money and access to a range of shops which are open when they need them, sell what they want at a price they can afford and which offer a reasonable choice of goods for sale.

For a disabled person, however, there may be additional issues. For example, access and transport might be difficult for a person using a wheelchair. Good lighting could help a student with a visual impairment. Can a person who is deaf be sure that all shop staff will be helpful and be able to communicate in sign language? Or will that person always have to have a signer/interpreter with them when they shop?

Many institutions quote lack of finance and resources as a reason for failing to meet these needs. But should a disabled person be discriminated against in this way? Why should Joanne, Janet and Emma not have the same educational and social opportunities as everyone else?

Legislation can help. The Disability Discrimination Act 1995 affects any business (shop, hotel, insurance company etc.) or public service (hospital, library, place of worship etc.) which provides a service, offers facilities or supplies goods to the public, whether paid or free. It does not include the provision of education (except in requiring schools to include information in their annual reports about their arrangements for admitting disabled pupils, how they ensure that disabled pupils receive the same treatment as other pupils and the facilities they provide to enable disabled pupils to access the education they are offering) or transport vehicles (except in allowing the Government to set minimum standards so that disabled people can use public transport easily).

The aim of the Act is to end the discrimination which many disabled people face and to give disabled people new rights in the areas of employment, access to goods, facilities and services, and buying or renting land or property. Some of these rights were introduced from December 1996; others are being introduced over a period of time.

However, legislation is only one aspect of the battle against discrimination

Any institution which is committed to equal opportunities can benefit from:

- talking to disabled people about what they want
- finding creative, user-friendly ways of meeting these needs. as Joanne, Janet and Emma demonstrate, needs vary.

## TEACHERS' NOTES UNIT 3: PART 2

### Notes for Activity Sheet 2

Activity Sheet 2 asks students to explore practical ways of providing three 'disabled' people with the same opportunities as everyone else. This is not just about how the actual buildings could be made more accessible but also about how attitudes might need to change before disabled people get the equality of opportunity they deserve.

### Specific ways in which a school could support someone like Joanne:

Carrying out an audit of the building to check how accessible it is to people who use a wheelchair. For example are there ramps in and out of buildings, dropped kerbs, kickplates on doors, lifts (safety is a key consideration here; are they tamper-proof? what about maintenance?), adequate toilet facilities, supportive seats in classrooms, height-adjustable tables with cut-outs for a wheelchair etc.? [N.B. Fire doors in corridors are a particular problem because of their weight but they are a legal requirement.]

### Make sure that everyone is well-informed about 01 and other conditions

Which may lead to the use of a wheelchair. Specific ways in which a school could support a person with Usher Syndrome or other students with impaired hearing and/or vision include:

Good lighting in all areas can help people with restricted vision to move around more easily. If stairs are dark-coloured, it could help to put bright lines on the edges (or dark lines if the stairs are bright).

### Make sure that everyone is well-informed about Usher Syndrome,

Retinitis Pigmentosa and other conditions which could result in loss of hearing and/or vision.

Encouraging students to get into a good, well-lit position when they communicate with a person who is hearing-impaired and not to give up if at first they cannot understand or be understood.

### The following apply to all schools:

Ensuring that the needs of disabled students are taken into account when making decisions about facilities (e.g. new shelves for the library, items of classroom equipment or improvements to the school grounds). Listening to what people who have a genetic condition and/or a disability have to say about how schools can best support them.

Being well-informed about equipment available from specialist suppliers.

**Changing attitudes, and thinking about the words we use, can be just as important as making changes to the physical environment. For example, a comprehensive secondary school in Wolverhampton has decided not to use the term special educational needs. Instead it has developed a Student Educational Needs policy because the school feels that all students fall somewhere along the spectrum of need.**

## STUDENTS' ACTIVITY UNIT 3: SHEET 1

### JOANNE'S STORY

Joanne is 22 years old. She lives at home with her mother and her two year old daughter Rachel. Joanne has a genetic condition called Osteogenesis Imperfecta or OI. She was the first person in her family to be affected by this condition. Soon after Rachel was born, Joanne found out that Rachel also has OI.

### HAVING A BABY

I'd always been told that I probably wouldn't be able to have children. When I found out I was pregnant, mum took me to my GP who referred me to the antenatal department of the local hospital. They put me straight in for a termination.

#### *At what point did you decide that you were going to have the baby?*

The day before I was meant to be going in for the termination. I knew that the baby had a 50/50 chance of having OI. Once I'd had time to think about it properly, I thought first of all I could be terminating a perfectly normal child and secondly even if she does have OI (which she does) medical techniques today are much better than when I was little.

#### *Did anybody give you a hard time about keeping the baby?*

Oh yeah! At the beginning I think nearly everybody was against it. My mum and dad have been divorced for quite a while and the first thing my dad said to my mum was, 'Oh well you'll have to persuade her to have the termination done' I did have an awful lot of problems during the pregnancy. Rachel was quite a big baby and when I was about four months pregnant, she's pushing up under my ribs which broke a couple of them. That gave me an asthma attack. I had to go to hospital to get the asthma under control and the second night I was there I was walking back from the toilets when my knee flipped back and I broke my kneecap.

It was funny really because they don't treat emergencies at the maternity hospital, so they had to get an ambulance to take me to another hospital to have my leg put in plaster! After the birth I also had a lot of back problems which we've since found out were fractures.

### MY CHILD HAS OI TOO

I'm mostly in a wheelchair but sometimes I'm alright to walk short distances. If Rachel has a break, we probably go up to the hospital in the car. Sometimes in hospital I get dirty looks from the new junior doctors in casualty if I walk in with her because I don't look typically 'disabled' when I'm walking. I have quite a bad limp but apart from that I look alright. And if you walk in with a child who has a broken leg, you do get dirty looks.

## STUDENTS' ACTIVITY UNIT 3: SHEET 1

### Joanne's Story continued

Why? Because they think perhaps I abused her. At the moment my mum is setting up a support group for 01 families who have been accused of abuse, and there are many of them.

#### **I MAY HAVE BRITTLE BONES BUT I'M NOT STUPID!**

We lived in Germany when I was little because my dad was in the army. I'd always managed in mainstream education in the British Forces schools. We came back to England in '86 and I started at a secondary school in Kirkham.

The first day I was there the headmaster made the big mistake of getting me up in assembly and saying to everybody, 'Be careful of this girl because she has brittle bones and if you knock into her, her bones will break'. So the fourth and fifth years thought, 'Right, let's throw her up against a wall and see what happens'.

I broke both my kneecaps, several ribs and my wrist. They just did it for fun to see what happened. After that I couldn't go back because of all my injuries. The educational psychologist came out to the house and said, 'We can't cope with her in mainstream education - she'll have to go to a special school' The people who did it weren't punished

#### ***Do you think you got the schooling you deserved?***

Oh no, not at all. Basically I refused to do any of the work because it was degrading. They tend to gear the classes to the lowest academic level in the class. When I was in the 16-19 unit, the mathematics we were doing consisted of cards with pictures of coins on and questions like, 'How many coins are there on this card?', 'How many 2p pieces are there?' etc. I may have a physical problem but there is nothing wrong with me mentally!

I would love to do correspondence courses but they're so expensive and the thing is we only live on allowances so life is quite tight financially. I did go full-time to college five years ago.

I started doing a course for people with disabilities to get into mainstream education but that work was also degrading. In the end I refused to do that course and I started doing foundation art and GCSE drama, but I only managed a week of that because they changed it to another building that I couldn't actually physically get into.

I don't really have many friends because I don't get out socially. I used to have friends at college but when I left to have Rachel they all sort of disappeared. The only friends I have are the carers who come in to help me and Rachel.

#### ***Do you find that difficult?***

Yeah, I do. Especially with my brother being two years younger than me. When I was 16 he was staying out late, had loads of friends and was always going to parties, and I was sat in watching TV.

## STUDENTS' ACTIVITY UNIT 3: SHEET 1

### Joanne's story continued

#### *Is there anything you could do to get more of a social life?*

I started doing a yoga course last year to help me relax at nights because I don't sleep very well. Social services paid for a carer to come with me. I had that for two weeks before the purchasing manager turned round and said, 'We can't fund a carer for you, we can only pay for you to go to a day centre'. Well at the day centre he's talking about everyone would be at least ten years older than me and most of them dribble.

It's like they're labelling you; 'Oh she's disabled, she's going to want to go to a place where disabled people are'. My social worker at the moment is trying to organise for me to go on a holiday but again the places where I would go would be for disabled people.

#### *Do you actually get out and about?*

I do sort of. Since September the Brittle Bones Society have bought me an electric wheelchair, which is the first time I've ever been able to get out on my own.

#### *Is that exciting?*

Oh yeah, very, very, very exciting! I mean you wouldn't believe that just going to the shops up the road would be so exciting! The only thing is that they think I've got a duff chair because it keeps breaking down, it's in Liverpool getting fixed at the moment. Last time it broke down was a bit scary because we were up at the shops. My mum went back to get the car but I don't know what I'd have done if I'd been on my own.

#### *Are there people around to help?*

Yeah, but they never do. I've just had my arm taken out of plaster today and the reason I broke it in the first place is that no-one would open the door for me so I tried doing it myself. That was in our local paper shop.

#### *Do you think it's because although you're in a wheelchair you look so...ordinary?*

Yeah, perhaps.

#### *What would you like people to do. Would you like people to offer to help?*

I don't know. Uuum... yes, it would be nice even if I didn't need the help. I can always say no. People do offer help but it's mostly older people. Some people will ask, 'Do you need any help?' which is great, but some say, 'Here, let me help you' and try to take over. There's the 'Does she take sugar?' syndrome as well. People assume that if you're in wheelchair you can't think or talk.

#### *How much are you able to do for yourself and how much do you need somebody to do things for you?*

Well it depends on fractures at the time. Most of the time I'm all right. The only thing that I do have problems with is bathing. I recently got a special chair from the Brittle Bones Society that lowers me into the bath. I have a stair lift as well and a ramp onto the back door...It's quite a well-equipped house. We had to leave our old house when it was repossessed, but within three weeks of moving here the housing association had done adaptations.

#### *If you could have one wish, what would it be?*

I'd wish for Rachel not to have any more breaks! That would be nice.

## STUDENTS' ACTIVITY UNIT 3: SHEET 1



### QUESTIONS FOR DISCUSSION

Which of the following words would you use to describe Joanne?

Healthy

Different

Disabled

Active

Unlucky

Happy

Unique

Special

*Be prepared to explain why/why not to the rest of the class*

In what ways have other people's attitudes towards Joanne affected her education, social life and expectations? Is this fair/right?

How do the words we use to describe people reflect our attitudes towards them? (You might find it helpful to think about how you would react if a person used some of the words in the above list to describe you.)

## STUDENTS' ACTIVITY UNIT 3: SHEET 2

### Don't label me, enable me

Joanne does not see herself as 'disabled'. She says, 'It's things like access and people's comments and stares which make me feel disabled'.

Janet and Emma have Usher syndrome (Type 1). This means that they were born deaf and also have RP (Retinitis Pigmentosa), a condition which limits their vision. They too feel 'disabled' by their environment and by other people's attitudes. You can find out more about Usher Syndrome from the Genetic Condition Card: Usher Syndrome.

### TASK

You have been given a piece of paper with two everyday activities on it. Your task is to think about what makes it possible for everyone to do these two activities, including people who use a wheelchair (such as Joanne), or have vision/hearing loss (like Janet and Emma).

Write down your ideas on the Task Sheet you have been given. An example is given below.  
When you have finished, think about the following questions:

Can you think of any reason why a disabled person should not have the same rights as everyone else?

Look at your Task Sheet. How many of your suggestions require changes to the physical environment, and how many require people to change their attitudes? Which do you think is more difficult to achieve?

How well do you think your school or college meets the needs of disabled people?  
If the needs of disabled people were always met, would we need the word 'disabled'?

### EXAMPLE:

ACTIVITY	What do we all need in order to do this activity	Anything else which Joanne might need?
Use the school library	Library must be open when students want to use it.  Might need help with how the catalogue works, finding things etc  More than one copy of books which everyone wants to use  A quiet area  Comfortable seats	Good access (i.e. lift if library upstairs). All on one level or ramps to avoid steps.  Someone to help if needed e.g. to open door? get books off high shelves? etc. Space between shelves, tables etc. must be wide enough for a wheelchair. Tables right height for a person using a wheelchair. Keyboards and controls on any IT equipment should have a light touch.

## STUDENTS' ACTIVITY UNIT 3: SHEET 2

### JOANNA

ACTIVITY	What do we all need in order to do this activity	Anything else which Joanne might need?

### JANET AND EMMA

ACTIVITY	What do we all need in order to do this activity	Anything else which Joanne might need?

## STUDENTS' ACTIVITY UNIT 3: SHEET 2

FOR PHOTOCOPYING AND CUTTING OUT INTO SECTIONS

A. HAVE A BATH/SHOWER	B. GO SHOPPING
C. USE THE SCHOOL CANTEEN	D. GO TO THE CINEMA, OR TO A PUB OR RESTAURANT
E. USE THE SCHOOL SCIENCE LAB	F. USE PUBLIC TRANSPORT
G. USE THE STAIRS	H. MAKE FRIENDS
I. TAKE PART IN SPORT	J. USE A TELEPHONE
K. COOK A MEAL AT HOME	L GO TO COLLEGE TO GET A VOCATIONAL QUALIFICATION

*Photocopy and cut out Give one slip of paper (with two activities on it) to each pair of students.*

## INFORMATION ABOUT JANET AND EMMA UNIT 3

### SHOPPING WITH JANET ITEM B

It was difficult going shopping with my two daughters when they were little. We would enter the store and find hazards all around — trolleys left in the aisles, goods waiting to be stacked on shelves, children running around, baskets on the floor at checkouts — and of course I tripped over them!

Once, when my daughter was a year old, I was with her in a queue at the newsagents waiting to pay for my paper, standing close to a birthday card stand. I paid for my paper and then walked home. Suddenly I noticed two white cards waving up at my eye level. I panicked and realised that she had picked the cards off the display stand. I then had to put them in the basket underneath the pushchair, feeling very guilty for not paying. A similar thing happened a few months later when I found a bag of oranges on my daughter's lap after I had been to the greengrocer's. I didn't know what to do. I was afraid of not being understood and I lacked the confidence to return them, although I think I could do so now.

### GO TO THE CINEMA, OR TO A PUB OR RESTAURANT ITEM D WITH JANET

'Usher people are sensitive to light in different ways. If there is poor lighting it is not easy to find your way around and it is difficult to concentrate on the displays or read information cards in museums. In pubs and restaurants, menus are often difficult to read if the lighting is poor. Toilets are often not bright enough and I often found it difficult taking my daughters when they were small.

Going out at night can be horrifying for me as I feel 'blacked out'. When going into cinemas or theatres it takes longer for my eyes to adjust to the light and I need to be guided by a reliable person, like a member of my family or a good friend.'

### WITH EMMA

Emma has just started her third year at Chelsea College of Art where she is doing a BA Honours degree in interior design. 'Once there was a photography week. I was embarrassed because I had to explain that I suffered from tunnel vision and night-blindness. I attended the dark-room session briefly but felt overwhelmingly isolated and scared.'

### PUBLIC TRANSPORT ITEM WITH JANET

I like to travel with a companion because I need the security and someone to tell me what is being said over the public address system. I can't always see the information board and they are not always working.

When I travel alone, I prefer to go at off-peak times because it is quieter. I need to move around slowly and I cannot relax unless I know what is going to happen at the end of the journey. When the children were small, I didn't travel alone with them as I would have found this too stressful. Just being out and about can be quite difficult. Whenever I go to school to drop off and collect my children, I have to look up and down on the pavements and roads as there are dangers everywhere for me. There are dogs and children running past below my visual level and of course I cannot hear them. Treading on mess when dogs have fouled the pavement, uneven paving slabs, tree branches overhanging the pavement and people who walk straight towards me and expect me to give way when I have neither seen nor heard them. People blocking pathways, children with bikes or skates, cars parked on pavements, rubbish bins, building materials and roadwork signs are all possible hazards. One bright morning a mother was running towards me with a pushchair. I didn't see them and yes, I fell over them with the mother yelling and screaming at me saying I should look where I was going. I was shocked and unnerved by the suddenness of it and felt very distressed.'

## INFORMATION ABOUT JANET AND EMMA UNIT 3

### ITEM G. USING THE STAIRS WITH EMMA

**Emma has just started her third year at Chelsea College of Art where she is doing a BA Honours degree in interior design.**

I remember I once complained to the central office about the grey stairs at the college. I asked them to paint white lines on the edges of each step, but they never did. I did get used to them, though I once fell over and that was quite a shock.

### AND JANET

At home I get frustrated and angry when my children rush about playing and I cannot hear them or see them properly. They bump into me or other things. It is just normal high spirits but a problem for me as accidents can happen. On one occasion, when she was little, I knocked my daughter down the stairs. I didn't hear or see her coming up to meet me.'

### ITEM H: MAKING FRIENDS

#### JANET

'I need people to understand that I am not only deaf but am also visually handicapped. I do not see people moving about, coming and going. I need to be approached from the front, maybe with a nice smile! If I am being introduced to people in a group, I like to be told the name of the person sitting on my right and my left. If we are eating and food or drink is placed on my side of the table, I like to be told so that I don't knock it over.

At times I feel very angry at the easy way that other people can communicate. I need someone to tell me what is going on and it is difficult to socialise when you don't know what is happening. When I am asked if I understand or am enjoying something it helps to know that people care and that I am not being ignored or treated as though I was stupid.

I feel unsatisfied in not being able to do some things without asking for help. I also find it difficult to get hold of someone who I can trust in awkward situations. I feel that I should not have to rely on my husband to take time off work to go with me and explain my needs. It would help if people knew about Usher Syndrome and were prepared to give time to the extra needs of our hidden disability.'

#### EMMA

Emma has just started her third year at Chelsea College of Art where she is doing a BA Honours degree in interior design.

'It has been quite hard. I didn't tell my fellow students straightaway that I have Usher because I found it too sensitive and personal to talk about. Some students wouldn't look me in the face or deal with me and had clearly never met a deaf person before. One said to me, 'You are brave to come here'. It's strange what a negative view some hearing people have of a disabled person. I'm not brave — it's just what I want to do.

Socially, I sometimes feel that I am the last person to know what is going on. Once I was in the studio and didn't realise that it was lunchtime — the other students had left without telling me. If someone says, let's go to the pub' and everyone gets upto go, I don't know what's going on unless someone actually says to me, 'We're all going to the pub,do you want to come?' When we have essays to do, the others discuss ideas and may get useful tips which I miss. I try to make an effort when I'm in a group,

## INFORMATION ABOUT JANET AND EMMA UNIT 3

### EMMA'S EXPERIENCES *continued*

but I do feel left out sometimes. I'm getting more confident now though and communicate directly with friends more than I used to. I do get annoyed and frustrated sometimes. Once my note-taker didn't turn up and I lost my temper. I couldn't bear the thought of all the problems I have to deal with and I really envied the others who could absorb information easily. But I do know that the tutors can't do it all for me — I am responsible for my needs too.'

### ITEM J USE A TELEPHONE

#### JANET

'Because I'm deaf, we have a minicom at home (a telephone which allows me to communicate with the caller by typing in what I want to say) and lights which flash when the phone or door bell ring. The strobelight for the phone helps but I do not always notice it. One very dark miserable morning I was sewing name tapes on my daughter's black swimming costume with the aid of a fluorescent table lamp which helps me to see. I was concentrating very hard with my eyes. I was suddenly alarmed by a flashing light and thought it was lightning as it was pouring with rain at the time. I later realised that it was my mum trying to phone me! I now have a pager which alerts me to the phone or door bell. This is very relaxing as I can go out in the garden or move around the house without having to worry.'

### ITEM K COOK A MEAL AT HOME

#### JANET

I need to know where things are so that I can move about comfortably and safely. I need the furniture to be left in a known position. I bump into doorframes and door knobs when I am overtired. I need to be warned of low objects and steps which other people may expect me to see. If I drop something very small on the floor, it is hard for me to find it. In my kitchen, if crockery and glasses are left on the worktop without my knowledge, they can get knocked over and broken. They are easier to see if they are placed at the back of the worktop and brightly coloured. The doors and drawers of kitchen units must be kept closed to avoid collisions. I have a waist-level cooker which makes it much easier for me to take out hot dishes.