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Background

The Royal Commission on Long Term Care reported its findings to the government in March 1999. Its main recommendation was that all personal care should be available (after assessment) according to need and should be paid for from general taxation whether it was provided by a care home or in the recipient's own home. This was rejected by the government. Instead, the government proposed to provide free nursing care for residents who are self funding and pay for their own care in nursing homes.

There are a number of problems with the government's approach

- The definition of nursing care is artificial and narrow: it only covers the time spent by a registered nurse not the care provided by nursing assistants who provide the majority of care to older people in nursing homes. This counts as personal care, covering tasks like bandaging and help with feeding and continues to be charged for.
- This tight definition means the terms will not apply to many people with Alzheimer's disease or other forms of dementia whose care is largely defined as "personal". This is unfair as people with other medical conditions - cared for in hospital receive all their care for free.
- Those who do benefit from nursing care payments will see little difference in their fees because the payments are insufficient. In England, the payments are worth just £35, £70 or £110 a week; in Wales, £100 a week. The average cost was £393 in 2001. Most people will still have to pay in excess of £300 a week for personal care and accommodation.
- Self-funding residents of residential care homes do not benefit from these payments and are still liable to pay the full fee for their care and accommodation (average cost, £280 in 2001).

Does free personal and nursing care simply protect the assets of the middle classes?

A report published by the Department of work and Pensions in January 2002 provided some valuable evidence in dispelling this myth. The report entitled *Self funded admissions to Care homes* examined the financial circumstances and dependency levels among older people who fund their admission in residential or nursing care. The report notes that,

- 61% of self funders had incomes of less than £200 a week

■ 9% were receiving income support

■ 70% of residents didn't have enough money to meet the weekly charges for their care, but had assets over £16,000 (the upper capital limit at the time of the survey)

These facts show that long term care policy continues to place a burden on people with low incomes. The desire for free funding of is therefore rarely about middle class people protecting and inheritance. It is more useful to examine the question of how as a society we respond to the needs of older an disabled people, at the most vulnerable point in their lives.

The capital rule means that any owner-occupier with a property worth more than £18,500 is forced to fund their care through the sale of their home. In today's housing markert the vast majority of people are caught by this rule. Most will have worked and saved for all their lives to afford their own home. Once their home is sold they are rerndered rootless, sure in the knowledge that they can never go back. Feelings of Loss of dignity, frustration and anxiety are common as people have to cope with losing their independence and their home.

The Scottish Parliament recognised these arguments choosing to fund free personal care in July 2002, which is in line with the views of the public. Mori found that 75% of the public thought that the government should provide free personal care. Long term care was also voted top priority by BBC viewers in a poll about urgent changes needed in the NHS.

Failings in the system of "free nursing care"

"Free nursing care" was introduced for people paying for their own care (self-funders) in nursing homes in England in October 2001 and in Wales from December 2001.

Although the system is still relatively new—cases are only now beginning to emerge to demonstrate how the system is working in practice—the evidence so far paints a disturbing picture:

- Many assessments have still not taken place despite the fact that they were due to be completed for self-funders in England by December 2001
- There has been little or no publicity. Many care homes do not seem to understand the system and there is a lack of awareness among self-funding residents and their relatives that they are even entitled to an assessment for nursing care payments

- Even where assessments have been carried out, payments have still not been made in many cases
- There are fears that assessments are budget-driven rather than genuinely concerned with the individual's personal needs
- There is no proper appeals process where assessments are in dispute
- A pattern is emerging of nursing homes pocketing the payments for themselves under the guise of fees going up.

What's wrong with attempts to put this right?

The case studies at the back of this document were put together before the department of health's announcement of 11 March, which set out new requirements aimed at preventing care homes from taking advantage of the new nursing care payments by raising their fees to residents.

Two points can be made in relation to these new measures. First, they do not appear to assist those who have already experienced fee increases. Second, it remains to be seen whether the new measures will actually achieve their stated goal. Requiring care homes to provide a breakdown of their fees and account separately for the NHS nursing contribution will not prevent the abuses that are taking place. Fee increases can always be attributed to some other cause, as the cases below amply illustrate. At the moment the system is such that unscrupulous care homes can take advantage of self-funding residents and we have no reason to believe that the new measures will alter this.

The Right To Care Campaign believes that the only fair system of funding the care of older and disabled people who have a long-term care need is by making all nursing and personal care free at the point of need, funded through general taxation.

- Overall personal care budgets are cash limited and needs assessments will have to be made within the context of the budget constraints
- Nurses responsible for making needs assessments may be placed in the invidious position of rationing care to individual patients
- A dangerous precedent is being set for narrowing the consensus of what constitutes universal free healthcare

The Right to Care Campaign Charter

The Right to Care Campaign believes:

- The recommendations of the Royal Commission on Long Term Care should be implemented in full
- All the care needs of the elderly and other vulnerable groups such as the disabled should be provided free at the point of use, without the stigma of means testing
- All nursing care, whether provided by a registered or non-registered nurse, should be provided on the basis of need and free at the point of use
- All the personal care and any other care needs of the elderly and vulnerable should be provided on the basis of need and free at the point of use

Right to Care Partners

PATRONS: Writer and broadcaster Claire Rayner; Robin Wendt, Royal Commission on Long Term Care; Lord Stewart Sutherland, chair Royal Commission into Long Term Care.

Alzheimers Society is the UK's leading care and research charity for people with dementia and their carers. Dementia affects one in 20 people over the age of 65 and one in five over the age of 80.

UNISON, the UK's largest union with 1.3 million members, including nurses, home carers, social services staff and other health workers.

Coalition on Charging - a consortium of 200 national and local organisations which oppose charging for essential non-residential social services.

NHS Support Federation is an independent alliance of NHS staff and the public who believe in a comprehensive NHS and support campaigns to protect and improve it.

National Pensioners' Convention - campaigning voice of Britain's pensioners, led by Rodney Bickerstaffe, and with a membership of one million older people.

Arthritis Care - represents 8 million people with arthritis - has 60,000 members but represent the whole community.

ACO - ACO is a network of over 200 charities and benevolent funds helping individuals in need - many of whom are older people. VOICES is a network of 50 registered charities providing a wide range of care services for older people throughout the UK.

Action on Elder Abuse - works with older people and groups to identify needs and strive, through research, campaigning and fundraising, to develop practical solutions.

Age Concern England

Age Concern Scotland - Age Concern cares about all older people and finds effective ways to make later life fulfilling and enjoyable. Nationally, Age Concern campaigns on ageing issues, undertakes research, provides information and advice and offers a wide range of training. Locally, Age Concern provides community-based services such as lunch clubs, day centres and home visiting. Age concern campaigns to make later life more fulfilling and enjoyable.

Carers UK is an organisation of carers, run by carers. It provides information and advice to more than 20,000 carers and professionals annually and campaigns for changes which will improve carers' lives.

Counsel and Care - advice and help for older people, their carers and professionals.

Leonard Cheshire is one of the largest charity providers of services for disabled people in the UK. Our 140 services support over 14,000 disabled people, offering flexible services to meet a wide range of needs.

MENCAP - campaigning and providing services for people with a learning disability and their families and carers.

Patients' Association - listening to patients; speaking up for change.

RADAR - is a national disability network, campaigning and lobbying for improved rights and services for all disabled people.

Relatives and Residents Association.

RCN, nurses professional organisation.

VOICES - a network of 50 charities providing a range of care services for older people

Campaign Checklist

1. Make sure your group is a member of the R2C Network so that you can receive regular information about the campaign.
2. Invite local groups and organisations to discuss and adopt a resolution supporting the Right to Care campaign
3. Use the R2C petition to gather support for the campaign.
4. Circulate the R2C campaign briefing paper to interested groups and individuals in your area.
5. Write a letter to your local paper using the campaign briefing paper to highlight this issue.
6. Contact your local Unison branch to hold discussions with care workers about how to support the campaign.
7. Hold a public meeting in your area and invite a speaker from the R2C campaign.
8. Conduct a small survey to find out about the state of care in your area.
9. Use the model letter to write to your MP asking them to raise the issue with ministers
10. Build support for a lobby of Parliament.
11. Keep the R2C campaign informed of what you are doing in your area.

What campaigning methods can I use?

There are many ways of getting your message across. In recent years, groups have experimented with ways to differentiate their campaign from others. In this section we will look at some of the more established methods, which are often still the most effective. However, it is a good idea to think as creatively as possible.

Letter writing

Letter writing can be effective in two ways. Firstly, you can write a letter as an individual, raising your concerns with decision-makers or developing contacts. Secondly, a large group of people can write similar letters to illustrate the strength of feeling on a particular issue.

Writing as an individual or group

At the beginning of your campaign, writing letters can be crucial in raising awareness of your issue. Try to make contact with local people of influence, as well as local groups and individuals, who you think will share your concerns. It is crucial to write in a way that will give your letter maximum impact.

- Make it clear what you want the decision-maker to do.
- Use clear and direct questions. Number them if necessary. This forces the respondent to address your specific concerns.
- Keep your letter short and to the point.

Letter writing campaigns

If you are co-ordinating a letter writing campaign, it can be a good idea to draft a model letter. This will ensure all letters sent are putting across the same message. The best type of model is where the basic facts are the same on each letter, but there is room for people to insert details of their own circumstances. This will highlight the impact of what you are campaigning about on particular individuals.

Writing to the press

Letters sent to newspaper editors can be an effective way to raise the profile of an issue. Local councillors and MPs always read the local paper to pick up on issues. Letters can often start a debate, which can then develop into a full-scale news story.

Writing petitions

Petitions can be an effective way of rallying support and drawing attention to an issue. They can also be a very useful method for identifying your supporters. You can formally petition your local

authority or Parliament, depending on the focus of your campaign. If you petition your local authority, you will get a formal response.

Presenting your petition

You can petition Parliament or a specific Government minister. This rarely leads to action by Parliament but is a useful means of gaining publicity. If you want to do this, the petition must be drawn up in a specific way. Particular wording is also required. Your local MP should also be able to find out the correct wording through the Journal Office in the House of Commons by asking for the "Rules concerning Public Petitions."

In recent years, Internet petitions have become a new way of campaigning. If you know someone with the right experience, they may be able to help you develop a website for your campaign. It shouldn't be too difficult for them to set up a petition, either through the website or through an e-mail campaign. This could be a very good way to reach a wider audience. Circulate your petition as widely as possible to your established networks and local services.

Publicity stunts

These are events that get media attention, but which don't challenge the law. Examples could be releasing balloons, or creating a photo opportunity such as a group of disabled people sitting outside the town hall in chains to emphasise the constraints of the community care system. The more original the event, the more likely you will be to get attention. ²⁷ These events can be a very good way to raise public awareness of an issue. They really depend on the media attending and running a story about it, so if you want to stage an event like this, make sure you brief the media effectively.

Leaflets

Leafleting can be an effective way to raise the profile of your issue. You can present information about your campaign in a simple and accessible way. Publicity will make the difference between having a large audience and a small one. Leaflets might be useful if you plan to have a stall in your town centre, particularly if you are trying to get people to sign a petition.

Leaflets are now relatively easy to produce as a lot of non-specialist computer packages (such as Microsoft Word) are now sophisticated enough to enable you to produce a professional looking document. There are three key tips for producing effective leaflets:

- keep it simple
- use large headlines, small amounts of text and lots of pictures
- make sure the print is easy to read.

You have little space in a leaflet, and most people will only glance at it quickly. You therefore need to think carefully about getting your key message across. Make sure people can find the information quickly. Try to limit the information to three key points, and present these as simply as possible. Imagine you are trying to get the message across to a typical twelve year-old. This will ensure you don't use jargon that might confuse people.

If there are public meetings coming up, make sure you put the details on your leaflet.

There are some legal requirements to consider if you are going to publish a leaflet. You must always include the contact details of your organisation. If you are a registered charity, you must include your registration number.

- Give the name of the group or person publishing the leaflet, along with contact details.
- Say if you are a registered charity and give your charity name and number, and your registered office address.

Holding a demonstration or a lobby of your local council

These can be an excellent way to get publicity, especially if a large number of people attend. Be prepared, however, for the possibility of the event being "hijacked" by other groups and causes. Also be prepared for a possible negative reaction from the local press (although press opposition can often be avoided if they are properly briefed before the event).

Before planning a demonstration, always think about how others will perceive your action, and whether this will help or hinder your campaign. A lobby of councillors on the evening they vote on your issue can be effective if it is peaceful, but if you annoy councillors with your attitude they might not vote for what you want. Similarly, if you want a local authority to create a new service, it is likely that a more co-operative approach will be more successful.

The success or failure of a demonstration or lobby will depend almost entirely on how many people turn up, so make sure it is well

advertised and that the press publicises the event. It can sometimes be a good idea to get a speaker to say a few words at the event to remind people why they are doing it. Ideally, the speaker should be someone who is affected by what you are campaigning about.

The media response to your demonstration is very important. Send out a press release before the event to make sure that the press know about it and can send a journalist. Journalists will almost certainly want to talk to somebody who is taking part, so decide in advance who is going to speak and what they will say. It may be a good idea to practice what you want to say in advance, especially if you think you may be nervous when you are interviewed. It is a good idea to contact the media after the event, to remind them of your version of events and why you held the demonstration.

Demonstrations have to meet certain legal requirements, so make sure you are aware of these.

Direct action

This is a campaigning method where the people involved take action which has a direct impact on the situation. For example, staging a sit-in to prevent your day centre shutting, boycotting goods, or lying down in the road to stop traffic.

Direct action may involve breaking the law. If you are in any doubt, you should seek legal advice before taking direct action. Although direct action can be very successful in raising public awareness, it runs the risk of alienating potential supporters. Some people may sympathise with the cause, but might be unwilling to support a campaign using these tactics, especially if they are breaking the law. Think carefully before you take this route and ask yourself if it is the best way to achieve your goal.

If you do want to undertake direct action, take legal advice and think through the implications carefully. Make sure that everybody who takes part agrees with the action and knows of any risks they may be taking.

How can your MP help your campaign?

One of the most common actions an MP can take is to write a letter to a government minister. An MP should get a non-standard response, directly from the minister. The MP may not agree with your point of view but is obliged to write to the relevant minister outlining your concerns and asking for a reply. The MP will then forward this reply to you. Other actions that MPs can take include signing up to a parliamentary motion showing support for a particular issue, asking a specific question in Parliament, or requesting a debate in Parliament.

MPs can also show support in all sorts of ways outside Parliament. They can write articles for local newspapers, for example, or highlight a concern when they speak in public .

Is it effective? Yes. The more MPs hear about an issue from their constituents, the more likely they are to take action. Do I need to be an expert? No, MPs need to keep on top of a wide range of issues. Often you will know more about a particular issue than your MP. And your MP may well be grateful for any information you can provide.

Does it matter which party my MP belongs to? No. The party in power formulates current government policy, but all MPs have influence that they can use in Parliament or in the Government.

What if my MP shows no particular interest in longterm care?

Even if your MP does not immediately appear to be interested in longterm care, it's essential for you to keep raising your concerns. It may take time to see results, but it is worth persisting. Ultimately it is always MPs' responsibility to pass on the issues you raise, whatever their own priorities.

MPs may well take up your case as an individual or group if you have already been in touch with other agencies (such as the local authority or the social services department) and have not had a satisfactory result. They can contact the agencies and take matters up with them directly. They will be more likely to take up a case for you if you are contacting them as a "last resort" and can show that you have already tried to sort out the matter yourself, but have hit a dead end.

MPs are also very useful if you are contacting the media. If your local MP is involved in an issue, you are more likely to get media interest in your campaign, which will mean more publicity. Photocalls with your MP are a particularly good way of gaining media interest. You can also ask for your MP's comments on an issue before you present your story to the press, television or radio. The media will be more likely to seek the opinion of the MP when they write the story. This will get the story more publicity and also make sure the MP states their view publicly.

If your MP sees a link between your issue and a wider problem, they will be more likely to take it up in Westminster. It is a good idea to look for ways in which your issue might be part of the wider political picture. A good MP should do what they can, both locally and nationally, to support your case, and should be able to give you an idea of how they can help you.

How to contact your MP

Remember that it is your MP's job to represent you. It doesn't matter whether or not you voted for them. If you don't know who your MP is, you can find out from the local library or Citizens Advice Bureau, or you can contact the electoral registration office at your local town hall. You can write to your MP or go to see them. You should always write first. Most MPs hold a "surgery" in their constituency, where you can see them personally. It is usually held once a week or once a month. Details of the surgery are often advertised in local newspapers, or you can try asking at your local library. Alternatively, you can contact them through their office at the House of Commons. Address your letter as follows:

Name of MP
House of Commons
London
SW1A 0AA

You can also telephone your MP's office there. The number is 020 7219 3000.

Meeting your MP

You can meet your MP at their surgery, or you can ask them to attend a more formal meeting with a group of you to discuss issues. This gives them a bit of information about your campaign and means they will have the time to find out more before you meet, so you will be able to have a more productive discussion. Keep your letter short and

to the point - preferably about one side of A4. Follow your letter with a telephone call to arrange a meeting.

When you meet your MP, be clear about what you want to say and what you want them to do. Bring your facts and show clearly why you need what you are asking for. Include somebody in the group who has personal experience of the issues you are talking about, so they can explain how they have been affected. If it is relevant, point out how many people in the constituency you represent, or how many people are affected by your issue.

Everybody has a right to visit their MP at the House of Commons and to ask to speak to them about their concerns. MPs have to make every effort to meet constituents when they do this. Making the effort to lobby your MP this way will show them you think the issue is really important. Mass lobbies of Parliament are a good way of letting MPs know how strongly people feel. Lots of people attending a lobby at the House of Commons can attract media attention, especially if the people attending represent different groups of people. Mass lobbies are usually organised by local or national pressure groups.

The advantages and disadvantages of a lobby of Parliament are very similar to a lobby of your local council. There are rules concerning lobbies of Parliament, so make sure you are aware of these. For parliamentary lobbies, you will need to contact the House of Commons' Sergeant at Arms. If you are expecting a large number of people, you should also contact the police.

How can resolutions help the campaign?

Tabling a resolution gives you the opportunity to explain the campaign to people who may not have heard about it yet. Having resolutions passed all over the UK by a wide range of organisations and groups will demonstrate the breadth and depth of support for free personal and nursing care. A resolution can specify particular actions that will be taken in support of trade justice and can provide a basis for further action.

Many different organisations can pass resolutions including:

- trade-union branches
- branches of political parties
- community groups.
- local church councils
- women's groups - for example, a local Women's Institute or Mothers' Union group
- local authorities - town or county councils
- students' unions

Think about the different sorts of organisations and groups in your area. There may be more opportunities than you think!

Where do I start?

Find out the date of the next meeting and check whether there is a particular format to follow to table a resolution. If you are approaching your local authority, there is usually a legal officer or a constitutional support officer who can explain the process. The resolution, or motion, will probably need to be tabled by a councillor rather than a member of the public, so find out whether any councillors are sympathetic to the campaign.

Passing a resolution is not an end in itself. The real impact will depend on how you follow it up. Above all make sure the action points in the resolution are actually carried out! Make sure that people hear about it - tell your local newspaper, parish magazine or organisation's newsletter about the resolution. Take a photo at the meeting where the resolution is passed or organise a photo stunt afterwards - this could accompany any articles that are published.

Sample Resolution

(Name of group/union/council) notes that:

1. The definition of nursing care is artificial and narrow: it only covers the time spent by a registered nurse not the care provided by nursing assistants who provide the majority of care to older people in nursing homes. This counts as personal care and continues to be charged for.
2. This tight definition means the terms will not apply to many people with Alzheimer's disease or other forms of dementia whose care is largely defined as "personal".
3. People receiving free nursing care are still having to top up these payments as they are too low or they have been assessed wrongly.

We believe

1. All the care needs of the elderly and other vulnerable groups such as the disabled should be provided free at the point of use, without the stigma of means testing
2. All nursing care, whether provided by a registered or non-registered nurse, should be provided on the basis of need and free at the point of use
3. All the personal care and any other care needs of the elderly and vulnerable should be provided on the basis of need and free at the point of use

We resolve to:

Support the Right to Care campaign by:

1. Writing to our local MPs to urge them to add their support
2. Encouraging our members/congregation (adapt as appropriate) to take part in campaign actions and events in support of trade justice.
3. Write to our national organisation/board/council (adapt as appropriate) to tell them about this resolution, and urge them to pass a similar motion of support/to become a member of the Right to Care campaign

Sample media release

Embargo: 0001 hrs 6 November 2001

Pensioners' lobby calls for 'cradle to grave' health care

Thousands of pensioners from across the country will descend on Westminster on November 6 for one of the biggest health lobbies of Parliament ever held. The event, organised by the National Pensioners Convention (NPC) and supported by the NHS Support Federation and the Community Care Protection Group, will involve over 200 pensioner groups as well as health care professionals and disability rights campaigners, in a call for better health care for older people.

The event will focus on the following issues:

- * The call to provide nursing and personal care free of charge, in whatever setting.
- * The abolition of the rules allowing for a reduction in the state pension after a six week stay in hospital.
- * The right to dignity on the ward for all patients.
- * The need to restore the principle of free health care from cradle to grave with no discrimination on the grounds of age, disability or social need.

The programme for the day's protest will be as follows:

- * 11-12.30pm - Pre-rally discussion from local groups and entertainment from the Riverside Jazz Band, Central Hall, Westminster.
- * 1-3pm - Rally in the Central Hall, Westminster. Speakers include: Jack Jones, Claire Rayner, Dr Richard Taylor MP, Prof Alan Walker, Prof Peter Millard, Prof Harry Keen, Faizullah Khan (Muslim Care), Keith Sonnet (Unison), Barbara Castle and Rodney Bickerstaffe.
- * 3pm onwards - Lobby of MPs in the Westminster Hall, House of Commons.

Rodney Bickerstaffe, NPC President said: "The care of older people is rapidly becoming a major political issue. The current care system is creaking at the joints with people having to sell their properties to pay for treatment, community care services under pressure to cope and hundreds of nursing homes closing every year."

"Even in hospital, older people are treated like second-class citizens having their pension almost cut in half simply for being sick. This is the only section of society that effectively has to pay for health care twice - once through their taxes when they were at work and now while they're lying in a hospital bed. This is the generation that built the NHS, worked in it, paid for it and is now being let down by it."

"Today we will send a clear message to the Health Secretary, Alan Milburn and the cabinet that older people should get the health and social care they deserve. And the country is rich enough to afford it without the need for half measures, compromises or means-testing."

Claire Rayner, NPC supporter and one of the commissioners on long-term care said: "Far too many older people in this country are being dreadfully let down by the system they trusted to provide all the care they would need when they became too old and frail to care for themselves."

"The NHS, which they were assured would provide 'cradle to grave' care will now provide only a limited amount of nursing care which doesn't include help with washing, feeding or going to the loo. This, the government says people must pay for out of their means-tested savings, and that includes the value of their homes. It cannot be right in a country as rich as ours to so cruelly mistreat the most vulnerable of its citizens in this way."

NHS Support Federation Director, Paul Evans added: "Most people still believe in a comprehensive NHS paid for in the fairest way out of taxation. The public didn't vote for a pay-as-you-go health service. User charges and uncontrolled private sector involvement will lead us away from the idea of health care for all. More often people will have to decide which health services they use, based on what they can afford."

ENDS

For more information contact NPC Press Officer Neil Duncan-Jordan on:

Useful publications

M. Lattimer, *The Campaigning Handbook, Directory of Social Change*, 1994. A comprehensive look at various techniques and strategies.

Useful websites

www.guardianonline.co.uk

www.nhs.uk/localnhsservices/default.asp - A full directory of English health services

www.nhs.uk/nhsguide/home.htm

www.parliament.uk - Look up people and offices, access information about papers and

www.nhs.uk/nhsguide/home.htm

www.epolitx.org.uk

www.askyourmp.co.uk - provide an easy way to search for Members of Parliament in the UK. The directory also contains MEPs. The contact details include preferred phone numbers and addresses, along with constituency names and in many cases e-mail addresses.

www.wrx.zen.co.uk/britnews.htm - All the national and regional newspapers published online. Major magazines

www.PetitionOnline.com provides - free online hosting of public petitions for responsible public advocacy.

www.bmj.com

www.kingsfund.org.uk

www.rightocare.org.uk

Progress of a bill

The first stage of this process is often the publication of a Green Paper. This is a consultation document that includes a series of proposals. It is designed to get responses from interested parties who might be affected by the proposals. Mencap always submits a formal response to proposals that are likely to have an impact on the lives of people with a learning disability.

The Government department then considers all the responses, and final proposals are drawn up. They are agreed by the Prime Minister and the cabinet, then published as a White Paper. Sometimes there will be further opportunity for comment at this stage.

If the Government decides legislation is needed to put its proposals into practice, it will develop a bill. It announces the bill in the Queen's Speech at the beginning of the Parliamentary session. Then the bill can go to Parliament. It can be introduced in either of the two Houses, the House of Commons or the House of Lords, but it has to be passed by both Houses before it becomes law.

First reading

This is really a formality. The title of the bill is read in the House and an order is made for it to be printed and made available for consultation before a second reading.

Second reading

This is normally two weeks later. This is the occasion for major debate on the principles of the bill. At the end of the debate, a vote is taken. If the vote is carried, this means the House accepts the bill in principle and it can go to committee stage.

Committee stage

A standing committee is established to consider the bill in detail. The committee looks at the bill line by line. This is when amendments and new clauses to the bill are taken for the first time. In the House of Commons, the committee is normally a group of between 18 and 40 MPs from all three main parties. In the House of Lords, the committee stage is taken on the floor of the house and therefore includes all the members of the Lords.

This is a good opportunity to lobby for changes to the bill by briefing MPs who are on the standing committee, and peers.

Report stage

When amendments accepted by the standing committee have been printed, the committee chair reports back to the House and brings the amended bill back to the House. The House then debates the amendments. Additional amendments can be introduced at this stage. This is the last opportunity to push for an amendment.

Third reading

This is the final opportunity to debate and vote on the amended bill. It is usually a formality and is often taken on the same day as the report stage.

The House of Commons and the House of Lords

A bill can start in the House of Commons or the House of Lords, but it must be agreed, with any amendments, by both Houses. If a bill starts in the Commons, it goes through all the stages there first and must then go through exactly the same process in the Lords. A bill starting in the Lords goes through the same procedure in the Lords first, and then in the Commons.

When the Houses do not agree, the bill is considered by each in turn until a compromise can be reached.

Royal Assent

When both Houses have agreed on identical versions of the bill, it is ready to receive Royal Assent, which is the Queen's approval. At this stage it becomes an Act of Parliament and passes into law.

Case Studies

In each of these cases the individuals concerned have contacted one of the organisations involved in Right to Care, often seeking help and advice. In many cases individuals have asked for their personal details to remain confidential and so the cases are presented anonymously.

The case studies in this dossier were assembled by the Right to Care Campaign over the month of February 2002 and suggest that the system is not working and is in need of reform.

Delayed assessments and payments

Case 1

A Citizens Advice Bureau in Greater Manchester reported that in one nursing home everyone was provisionally assessed as being on the £70 rate. They were told to reduce their payments accordingly until an individual assessment took place. However, individual assessments took some time and residents who were subsequently assessed as being entitled to the £35 rate for free nursing care then found themselves owing substantial sums to the home. In one case it took 13 weeks for the individual assessment to take place and the resident was then billed for the £450 shortfall. The money had been spent in the interim and the resident's family were concerned as to how the bill would be paid.

Case 2

Mr A contacted the Relatives and Residents Association advice line in January 2002. He has been told his mother has been assessed for the middle band of free nursing care—£70 a week—but he has received nothing in writing. He has been unable to contact the nursing home co-ordinator and has been told by her secretary that she is not taking calls. The reason given for nothing being put in writing is "lack of money".

Case 3

Mrs B's daughter is a UNISON member. She writes:

"When Mum went into a home, we had to sell her house to pay for her care. I still cry now when I think of it. She had lived in that house for 60 years. Mum was not rich—she was surviving on Income Support. The sale raised £70,000. It has broken my heart. Thankfully, Mum does not know what has happened—and she could not remember her house now anyway.

"Because of her stroke, Mum doesn't talk and she cannot walk. We have had to change her home as the nursing care was poor in the first home. Her weight fell

from 11 stone 4 lbs to 7 stone 2 lbs. Now she is in a good home in Liverpool run by a charity but it costs £1,400 a month and as a self funder—because she owned her home—mum has to pay the full amount herself .

“In January this year I found out from UNISON that my mother should have been entitled to help with her nursing care payments since last October. Because of this I pursued the home about it. No one seemed to know anything. They just kept fobbing me off. I have power of attorney over my mother’s affairs but I was never informed that she was entitled to have a nursing care assessment. I wonder how many other self-funders—particularly those who don’t have relatives to lobby for them—have been told of their entitlement. Why has there been no publicity from the government about this?

“Finally, I was informed in February 2002 that she had had her assessment and was entitled to £110 a week. We have yet to receive the money. Although it will be a big help, it is well short of the monthly fees charged by the home.”

Case 4

Mrs M’s son is a UNISON member. He writes:

“My mum first became ill in mid 1997 when she was 63 years old. She had led a very active life and showed no signs of succumbing to such a debilitating illness as shingles on the brain. She spent over four months in hospital, two in intensive care.

“Mum was left with permanent brain damage, in fact her mental condition was similar to that of someone in the latter stage of Alzheimer’s. She was discharged into residential care. Her husband had died five years earlier and I lived 60 miles away. Because Mum owned her own house and had other assets she was assessed for self funding.

“I was granted receivership of her estate. The family home had to be sold quickly to release funds to finance Mum’s care and consequently achieved about £10,000 less than its worth. The residential care home fees were approximately £800 per month.

“Over the next 30 months Mum’s health slowly deteriorated, she became a wheelchair user and her mental powers declined further to the point where she could no longer recognise me or pictures of her husband.

“She was reassessed for nursing care and entered a private nursing home in Hitchin, North Herts, in September 2000. There are no council or voluntary homes left in the area. The fees are currently £2,300 per month. She needs help to wash, dress, go to the toilet, eat, drink and get around. She has to be lifted into and out

of bed and the bath and spends her days sitting in her wheelchair living her life from half hour to half hour, as that is all her memory appears to retain.

“Six months after it was first introduced, Mum has only just been assessed to find out whether she qualifies for the government’s “free nursing care”. She was awarded £110 per week but the arrangements are not yet in place for the payments to be transferred from the local authority to the home—so she’s still waiting to see the colour of the money!”

Assessments seem to be “budget driven”

Case 5

Mr C contacted Help the Aged concerning his aunt, who has a self-funding place in a nursing home in the north of England. A month after the introduction of “free nursing care” for self-funders neither the home nor the local authority knew precisely how the scheme would work. A letter to health secretary Alan Milburn elicited an eventual but uninformative reply from a member of his administrative team. The health authority finally clarified the scheme. They subsequently wrote to Mr C, who has power of attorney for his aunt, inviting him to attend the assessment that same day. Mr C was unable to attend at such short notice but spoke to the nurse assessing his aunt. She confirmed that his aunt, and indeed most people, would end up in the middle band even though her needs were quite intense. Mr C feels that the government clearly intends to place most people in the middle or lower band and that the whole scheme is budget driven, rendering the assessment process pointless.

No appeals process where assessment is in dispute

Case 6

Ms D contacted the Relatives and Residents Association. She has an elderly aunt who is self funding her care in a nursing home in Dorset. She was “assessed” for nursing care worth £35 per week by an assessor who did not see the residents but went through the details of self-funders with the manager of the home. Ms D is a former nurse and believes her aunt should be at least in the middle band of assessed need. However, there is no proper appeals procedure where the assessment is in dispute.

Nursing homes keeping nursing payments or raising their fees

Case 7

Mrs E’s case was reported to Help the Aged. Mrs E, aged 91, lives in a nursing home in the south of England and is paying for the fees through her savings. The fees went up by £30 in September 2001. A month later, Mrs E’s daughter received notification from the Trust regarding the new “free nursing scheme”. At the same

time she received a letter from the home saying they were going to re-assess their residents and adjust the fees to reflect their individual nursing needs. As a result, Mrs E's fees were increased by a further £75 a week. She has since been assessed by the health authority that has awarded her the middle rate of £70 per week. As a result, Mrs E is worse off by £35 a week.

Case 8

Mr R called the Alzheimer's Society helpline. His sister-in-law is self funding and he has just received a bill showing a reduction of £70 for nursing care, but an increase of £116 for other things. The reasons cited were higher costs of employing nurses and the costs of registering under the new care standards.

Case 9

Mrs F contacted Age Concern with her story:

"After a heart attack in March 1997, my mother-in-law entered a nursing home. We have been highly satisfied with the home but were very relieved when we heard last October that government funding would henceforth be provided for the nursing care and she would only have to pay for her personal care and accommodation. My mother-in-law sold her home to pay the fees.

"We now understand that after discussion with other homes in the area, they are not planning to reimburse to my mother-in-law the £70 per week which it has been determined she needs. In October, my mother-in-law's fees were increased from £16,817 to £17,680 per annum to take account of the increase in the minimum wage. With NHS funding this takes the fees received by the home to £21,320. Apart from administration costs, nothing extra is provided to justify an increase in the total paid to the home of approx 27 per cent!"

Case 10

Mrs P's case was recently highlighted in the Mail on Sunday after her relatives approached Age Concern. Mrs P is 92, has dementia, is frail and needs help to walk. Mrs P is in a Norfolk nursing home and by February this year had still not been assessed for free nursing care. However, her son, who has power of attorney over her affairs, received a letter from her care home, which is one of a chain run by a large company, stating that his mother's fees of £383 a week would increase by whatever sum her nursing assessment determined she would be entitled to. If she is placed in the top band of nursing need—£110 a week—this means her fees will increase by 29 per cent. The home increased its fees last year by 10 per cent.

Case 11

Mrs F, whose husband had been a self-funding resident in a nursing home since 1998, contacted a Citizens Advice Bureau in Dorset. Her husband has been assessed as eligible for the £70 nursing care rate. But the home has written to the

relatives of all residents saying that only the lower rate of nursing care, £35, would be allowed against the nursing home fees regardless of the actual rate of nursing allowance the individual is entitled to. So in his case, the fees he has to pay have been reduced by £35 rather than £70.

Case 12

The same Dorset Citizens Advice Bureau reported that another home brought in a price increase of £27 to coincide with the introduction of free nursing care, thus virtually nullifying the £35 rate. The same home has been very slow in returning overpayments where the individual assessment showed that the resident was entitled to the £110 rate.

Case 13

Ms G contacted the Relatives and Residents' Association advice line. Ms G's mother has been in a care home for three and a half years. In October, the home advised her that her mother would be assessed for nursing fees and payments would be backdated. In January, the home advised her that a fee increase effective from the middle of February would take up all the nursing care payment her mother was entitled to. Ms G is horrified that the home can declare an increase of this sort when they still do not know what the assessed nursing payment will be.

Case 14

Mr H contacted the Relatives and Residents' Association advice line. Mr H's mother has been a self-funding resident of a nursing home for the last two years. Mr H was informed by the home that fees have increased by the amount of the assessed free nursing payment and that the backdated sum will not be paid because the health authority has not paid it, a fact established by Mr H to be untrue. All the affected relatives protested to the home and received a letter stating that they should not adjust their fees' standing orders as the home would be keeping the nursing care payments. One relative, who did deduct the assessed nursing care payment from the fees cheque, was told that if he didn't pay the disputed amount his mother would be evicted.

Nursing home refuses to pass on backdated payments following a resident's death

Case 15

Mr I contacted the Relatives and Residents' Association. Mr I's mother had been abused and neglected in her original care home. Following her emergency admission to a very good alternative nursing home, she died three and a half weeks later. Mr I paid the fees of £425 per week for six weeks in advance. He is now owed a total of £1,190 by the home—for two weeks' payments made in advance covering the period after his mother's death plus £340 paid by the NHS

Trust to the home for backdated nursing care payments. Mr I has however subsequently been given a copy of a contract stating that no fees were refundable for any reason.

Case 16

Mrs J also contacted the Relatives and Residents' Association helpline. Mrs J's mother-in-law was in a Kent nursing home where she died on 25 December. She had been paying fees for the past five years. She had been assessed as being entitled to £70 a week for nursing care, backdated to 1st October. However Mrs J has received a bill for a month's fees of £2,000 "in lieu of notice". She knows that the room was filled the day after her mother-in-law died. She cannot believe the insensitivity of a bill at this time, or the home being able to justify charging for a month's fees after a death. Her mother-in-law's home was sold to pay for her care. All benefits have now obviously been stopped so she and her husband face the prospect of having to find the £2,000 themselves.

Glossary - NHS explained

The pace of current reform to the NHS is very rapid below are explanations of some of the new structures and organisations to appear.

Commission for Health Improvement (CHI)

The CHI will act as an independent inspectorate to ensure standards set by the Government, through its health policies and NSF, and clinical guidance provided by NICE, are met. Local health care organisations in the NHS will be reviewed every three or four years. It also has the power to carry out or assist in investigations and enquiries into serious service failures. CHI will help NHS organisations draw up action plans to tackle problems or areas of weakness, providing expert support and advice drawn from the best service providers. The CHI was set up in October 1999.

www.doh.gov.uk/chi/

Health authorities

England's 95 health authorities ceased to exist from April 2002 and passed many of their responsibilities to primary care trusts. They have been replaced by 28 larger health authorities. These will be known as 'strategic health authorities' from October 2002.

These new strategic health authorities will be responsible for developing strategies for local health services and ensuring high-quality performance. They will manage the NHS locally and will be a key link between The Department of Health and the NHS. They will also ensure that national priorities, such as programmes for improving cancer services, are integrated into local plans.

National Institute for Clinical Excellence (NICE)

NICE is a new body set up in April 1999 to promote the highest quality of treatment and technology in the NHS and the cost-effectiveness of NHS services. It gives advice on best clinical practice to the NHS, to those commissioning NHS services (strategic health authorities and primary care groups / trusts), and to patients and their carers.

NICE is a partnership between the Department of Health, the NHS, health professionals and patients. Guidelines set by NICE will be used across the country, helping to end geographical variations in care that have grown up in recent years.

National service frameworks (NSF)

NSFs help establish clear national standards for services to improve quality and reduce unacceptable variations in standards of care and treatment. There are NSFs for coronary heart disease, mental health, older people, and the NHS Cancer Plan. NSFs for children, diabetes, and renal (kidney) services are also being developed.

www.doh.gov.uk/nsf/coronary1.htm
www.doh.gov.uk/nsf/mentalhealth
www.doh.gov.uk/olderpeople.htm
www.doh.gov.uk/nsf/renal.htm
www.doh.gov.uk/nsf/children.htm
www.doh.gov.uk/nsf/diabetes/index.htm
www.doh.gov.uk/cancer/cancerplan.htm

NHS trusts

Hospital trusts are found in most large towns and cities, and usually offer a general range of services to meet most people's needs. Some trusts also act as regional or national centres of expertise for more specialised care, while some are attached to universities and help to train health professionals.

Trusts can also provide services in the community - for example through health centres, clinics or in people's homes.

Except in the case of emergencies, hospital treatment is arranged through your GP. This is called a referral. Appointments and treatment are free.

Together, NHS trusts employ the majority of the NHS workforce including nurses, doctors, dentists, pharmacists, midwives, health visitors and staff from the professions allied to medicine, such as physiotherapists, radiographers, podiatrists, speech and language therapists, counsellors, occupational therapists and psychologists. Their many other staff include receptionists, porters, cleaners, IT specialists, managers, engineers, caterers, and domestic and security staff.

Primary care trusts (PCTs)

PCTs are the cornerstone of the NHS, responsible for the planning and securing of health services and improving the health of the local population.

For example, PCTs must make sure there are enough GPs to provide for their population and that they are accessible to patients. PCTs must also ensure the provision of other health services including hospitals, dentists, mental health care, Walk-In Centres, NHS Direct, patient transport (including accident and emergency), population screening, pharmacies and opticians. In addition, they are responsible for integrating health and social care so the two systems work together for patients.

The 303 PCTs in England will be given the funding to plan and commission health services for their local communities - a role previously carried out by health authorities. Eventually they will control 75 per cent of the NHS budget. It also means that decisions about local services are made at a local level by those best placed to make them

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