

M F T
HANDBOOK

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Handbook
2003

The Macfarlane Trust

IS REGISTERED AS A CHARITY

NO: 298863

THE TRUST IS GOVERNED BY TEN TRUSTEES

Six Trustees are appointed by the Haemophilia Society:

Peter Stevens ♦ London
Christopher Hodgson ♦ GRO-C
Anthony Yeaman ♦ GRO-C
Gordon Clarke ♦ Ireland
Tracey Morgan ♦ GRO-C
Stuart Gregg ♦ Warwickshire

Four Trustees are appointed by the Secretary of State for Health:

Elizabeth Boyd ♦ London
Dr Mark Winter ♦ GRO-C
Patrick Spellman ♦ North Yorkshire
Roger Tyrell ♦ London

The Trustees act in a voluntary and honorary capacity. Overall policy is created and monitored through four formal meetings each year plus extraordinary meetings if required. In addition the Trustees support and direct the staff through regular contact and correspondence plus committee meetings and telephone conferences as needed. See pages 12 and 13 for brief personal details.

The Deed, constituting the Trust, says that the objects are to:

'relieve those persons suffering from haemophilia who as a result of receiving infected blood products in the United Kingdom are suffering from Acquired Immune Deficiency Syndrome or are infected with Human Immunodeficiency Virus and who are in need of assistance or the needy spouses, parents, children and other dependants of such persons and the needy spouses, parents, children or other dependants of such persons who have died.'

Registered Office: Alliance House, 12 Caxton Street, London SW1H 0QS

MFT

Handbook

FOREWORD

The Macfarlane Trust exists to give help to people with haemophilia who have to cope with the effects of living with HIV infection, and to their families and dependents. This handbook, which up-dates the previous issue, aims to give information about the help available.

Please read this Handbook carefully. There have been changes since the last Handbook was issued in 2000; these changes might affect you, so do not be misled by any similarity in appearance into thinking that the content is unchanged.

These changes are most important in the key sections dealing with the Trust's policies and with the welfare benefits system. The Trustees and staff do their best to provide all the information needed for Trust beneficiaries to obtain the maximum income possible from these sources, and the staff will help where they can; but each beneficiary has the final responsibility to maximise the income that can be legitimately drawn from benefits and from the Trust Fund.

The needs of registrants are changing all the time, and the Trustees do their best to understand these needs and to develop policies that are adapted to these changes. It is possible that some policies described in this Handbook will soon be superseded; if this happens, notice of the changes will be made available to everybody who needs to know them just as this Handbook has been.

Throughout its life the Trust's policies have also had to be tailored to the availability of funds. Since it was set up in 1988 with a Trust Fund of £10 million, the Trust has received further funds from the Department of Health that brings the total received by September 2002 to £27 million. Investment activities have added to this total, enabling the Trust to have disbursed, by the same date, some £31 million while still having over £6 million in cash and investments. Had more funds been available, there have always been needs that the Trustees would gladly have addressed; they expect to have to continue to make difficult choices in the future. Registrants and their families must, therefore, expect to continue to face occasional disappointment when the Trustees cannot help meet needs that the Trust cannot afford.

The Trust will always seek, and urge applicants to seek, contributions towards meeting requests for financial help from other sources. This issue of the Handbook, like its predecessors, gives information about such sources and how to apply to them. It also sets out the non-financial help that the Trust and other organisations can give.

While the Handbook will continue to be the primary source of information, it deals with some complex issues and cannot answer every question. The staff will always be pleased to help with specific enquiries. Staff and Trustees will also always welcome suggestions of improvements, not just to the Handbook, but to all aspect of the Trust's work.

Peter Stevens
Chairman of Trustees

INTRODUCTION

The Handbook aims to tell you what help you can get from the Trust and other sources, and how best to go about it. For the Trust in particular, it tells you not only about financial help, but about information, advice and support. The majority of this applies to dependants and carers as well as the persons registered with the Trust.

HOW TO USE THIS BOOK

Please remember that this is not a book of rules. The essence of Trust operation is directed by the Trustees, and thus although for fairness and efficiency we must have some set procedures there is very often scope for discussion. The Handbook is therefore just a guide - it tries to explain what can be done and how to go about it - please read it and refer back to it when your circumstances change, but do not regard it as unchanging and unchangeable. **Above all please ring the office when in doubt.**

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This section explains the advice and guidelines that the Trust can give or obtain for you on many of the common problems of everyday life. It includes sections on Mortgages, Housing, Benefits, Finance and Investments, Legal matters (including Wills), and Health. **These pages are just a summary; if in any doubt - phone in.**

STATE WELFARE BENEFITS

This section aims to give to basic information on all the benefits that you might be eligible for. Not all apply to everyone. **When making benefits applications please ring the office.**

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FINANCE

FINANCIAL HELP FROM THE TRUST

Financial help from the Trust is available where there is a need, in particular to help with the extra costs of living arising from HIV. There are three forms of payment available from the Trust, regular payments, winter payments and single payments. The overall objective of this system is to relieve people of having to ask repeatedly for help by giving individuals as much control as possible over their spending, and the maximum choice of priority to suit their own needs.

How you use your regular monthly payments is entirely your choice, and the Trust expects that with this help individuals should normally be able to budget for routine expenditure. However, it is recognised that not all expenses can be budgeted for. Single payments are, therefore, made to help towards meeting needs that cannot be met from regular income.

Please remember that the Trustees are bound by law to exercise their discretion in meeting needs. Although some general guidelines can be drawn, the Trustees cannot presume that everyone has the same needs. There can be no 'entitlements' or automatic and standard responses to requests for financial help.

On the other hand, there is very little the Trustees cannot consider provided that they take account of the long-term needs of the Trust, and do not compromise the welfare of the whole community for the sake of an individual or a minority group. There is therefore no need to look for outside advice on what the Trust will or will not do; always ask us. In order to be fair and consistent, the Trustees may have to refuse help for things, or at levels that could not be afforded for all similar cases, or they may have to offer a different solution from the one you propose.

TRUST PROCEDURES

Applications

We aim to keep everything as simple as possible. We have enclosed a form, but you do not have to use it if you would prefer to write a letter. The form exists in case anyone finds it easier than a letter and as a reminder of the information we need. See page 8 for details. If you have access to the Internet, you can go to the Trust's Website and complete an application form, which can be e-mailed, or printed off and posted to the office.

Staff Authority

For many of the more common types of payment the Trustees have authorised the staff to make immediate payments provided that the application falls within limits fixed by the Trustees. These limits exist only to enable a large number of requests for help to be dealt with speedily without having to wait for consultation with the Trustees. The Trustees of course retain discretion to go outside the limits if they consider the need justifies it and Trust resources will permit.

The staff can advise on the kind of help the Trustees may be able to approve, but they do not refuse any requests. Every application, which is outside the delegated authority of the staff is referred to the Trustees for their decision.

Review

Anyone not satisfied by a decision on a request for help can write and ask the Trustees to review their decision. Normally it would be expected that some fact or circumstance not previously included, or insufficiently presented in the first application, would be given to justify a review.

Anonymity

Applications are put to the Trustees anonymously.

Confidentiality

We would like to stress our absolute commitment to the confidentiality of your affairs. Information you give us is used for Trust purposes only when seeking to assist you. We are registered under the Data Protection Act but apply limitations stronger than even required by the Act. The only time we would discuss your affairs with anyone else would be with your express consent to enable us to negotiate with someone on your behalf.

The regular monthly, winter and single payment systems are described in detail in the following sections. Anyone in any doubt about how or whether to make an application should contact the staff for advice.

REGULAR PAYMENTS

Following a review of Trust payments in 1998/9, regular payment rates were substantially increased with effect from September 2000. A further review of needs will be undertaken in 2003, but it is unlikely to lead to major revisions of rates.

Who can have a regular payment?

Everyone registered is eligible for a monthly payment at some rate - just ask. If later your circumstances change, please contact the office staff who will reassess the rate. Since personal circumstances can change, the office reviews all individual payments from time to time. This results in five to six increases for every reduction made, but when a reduction is found to be necessary, at least three months' notice is given.

What are payments for?

Regular payments are intended to help you and your family meet the additional costs of living with HIV related illness.

Rates

The current monthly rates are shown in the panel on page 6.

Procedures

Regular payments are made monthly to a bank or building society account. Payment is made on the 16th of the month or the Friday before if the 16th is a weekend or bank holiday. Because we use a direct system, the money is available to you on the same day in almost all cases, though there may be a delay if you are using a Building Society savings account. Your bank statement shows the source of the credit simply as MFT.

For any change of your account, we need to be told in writing not later than the 9th of the month. In an emergency or for the short-term, payment can be made by cheque.

WINTER PAYMENTS

The extra costs of living with HIV are not the same all the year round. In particular, the cost of keeping warm increases in winter as may the cost of a good diet because fresh fruit and vegetables tend to be dearer. The Trustees considered allowing for this by increasing regular payments made during winter months. But, because home heating bills usually arrive as single large amounts, the Trustees provide a single lump sum payment, to be made in November.

Everyone who is HIV positive (registered persons and partners) is eligible for this payment, which is made at a flat rate irrespective of means.

Because this payment is a seasonal boost to the regular monthly payment, all those who receive a regular payment from the Trust will automatically be credited with the winter payment in November, separate from and a week before the monthly payment. Hence, anyone who has opted not to receive the monthly payment but who wishes to receive the winter supplement should write or telephone the Trust Office and a payment will be made.

The Trustees review the amount paid each year and for the time being have decided not to change the rate of £525 set in 2000.

SINGLE PAYMENTS

Following the Payments Review held in 1999 and the consequent increase to Regular Payments, Single Payments to those registered are restricted to health related needs only. Applications must be supported by an up-to-date medical report and a supporting letter from the Centre or GP. Payments to widows and dependant children do not require medical support unless the widow/partner is also disabled.

All single payments are made within the Trustee's discretion. There is no rigid set of rules and regulations laying down the goods and services for which payments can be made. Equally, although the Trustees aim to be as consistent as possible, no one payment creates a binding precedent when considering similar requests.

However, experience shows that all but a very few payments fall under five broad headings, which represent the areas of highest priority for help from the Trust.

Under each heading it is possible to identify particular categories of need which members think are vital. Guidelines have been drawn up for these in order to achieve as high a degree of consistency and fairness as possible.

In most cases the guidelines have been set to limits, which allow staff to deal with over 80% of the requests received without further consultation with Trustees. These requests can usually be cleared in under a week.

The types of payment covered by these guidelines are described in the panel on page 7. This should not be treated as a comprehensive list of every type of help available.

Please do not rule out asking for something simply because there appears to be no guideline covering your request. Equally there may be conditions involved and there are certainly financial limits, so please therefore always check with the Office before you actually commit yourself to any expenditure.

See page 8 for "How to apply for help".

Regular Payment Monthly Rates

For people registered

A Standard Rate available to all registrants£255

This rate plus additions, where applicable, is payable to anyone whose circumstances do not qualify them to receive the Higher rate shown at B, plus the following additions as applicable:

for partner£11
for each dependant child£11 each

B Higher Rate available to those in receipt of any of the following benefits: Income Support; Income-based Jobseekers Allowance; Student Loans; Working Tax Credit; Housing Benefit; Council Tax Benefit

Higher Rate£305

Plus any of the following additions:

for partner£30
for first dependant child£30
for each other dependant child£6 each

For Partner who is HIV positive:

Standard Rate£255

(Payable in addition to whatever rate the registered person receives)

the registered person will not receive any additional partner's allowance under A or B above if a positive partner receives this payment.

For Registered Person or Partner who is HIV positive and who receives the Higher or Middle Rate Care Component of Disability Living Allowance (or Attendance Allowance)

Supplement Paid in addition to any of the above£61

For Widows and Dependants

For six months following bereavement, widows receive whatever rate had been in payment to their partner, except for the supplement payment. A transition payment is also available for those caring for orphans.

After six months following bereavement, widows whose circumstances are not described below will be paid £100 per month, for a further nine months.

Widows who are themselves HIV positive will be paid without time limit at the appropriate rate for a registered person (i.e. A or B - see Note 1).

All other widows will be paid at the following monthly rates for as long as their circumstances remain as described:

if incapacitated (see Note 3)£100
for first dependant child£100
for each other dependant child£30 each
on Income Support, Income-based Jobseekers Allowance, Working Tax Credit, Council Tax or Housing Benefit and having dependant children£30

- Notes
1. If the appropriate rate is higher than was being paid to the partner, the widow's rate will be introduced immediately.
 2. Guardians/carers of orphans will be paid the same rates as widowed mothers.
 3. Incapacitated means in receipt of Incapacity Benefit (IB) or Severe Disablement Allowance (SDA). Incapacity is also established if in calculating entitlement to IS, HB or CTB the disability premium has been included in the applicable amount.

TYPES OF SINGLE PAYMENTS

Payments are made to provide or contribute towards:

Health –

- ✓ Nursing Care: Agency nurses employed to look after someone at home. This is offered as a top up to what is provided by the health authority or as a stop gap whilst a care package is put together.
- ✓ Equipment for Disability: Items of equipment such as wheelchairs, stairlifts. Some equipment may be provided on a long-term loan basis.
- ✓ Complementary Therapy: Trial sessions of complementary therapies provided by qualified and accredited therapists: available to a partner/carer as well as the member.
- ✓ Convalescence & Respite: Convalescence breaks taken shortly after a hospital stay due to a HIV related illness. Respite breaks on medical recommendation only.
- ✓ Special Chairs/beds: Reclining chairs/beds as recommended by an Occupational Therapist.
- ✓ Assisted Conception: The Trust will contribute towards ancillary costs of assisted conception such as overnight stays and travel but is unable to help with the cost of treatment.

Mobility –

- ✓ Motability: Deposits on Motability hire cars and new and used cars bought through the Motability scheme. To those receiving DLA(M), similar payments are available when buying a new or used car independently.
- ✓ Hospital Fares: Travel costs incurred during an acute phase of a person's illness & travel costs of close family members visiting a member in hospital (where these cannot be paid through the hospital fare scheme).
- ✓ Driving Lessons: Course of driving lessons taken by the member or, where he/she is to ill to drive, spouse, parent or carer.

Accommodation –

- ✓ Setting up Home: Furniture and equipment required by a member setting up home for the first time.
- ✓ House Move: Incidental costs of house purchase (i.e. not towards purchase price) and removal costs, where the move is related to health needs.
- ✓ Special Adaptations: Where the Local Authority has approved a Disabled Facilities Grant and there will be significant delay in making payment or the payment will be less than the cost of work to be done, the Trust may make a contribution to enable work to proceed. Where the Local Authority have acknowledged that such a grant would be payable if funds permitted, Trustees may consider an application for help to allow work to take place.
- ✓ Central Heating: Repairs to existing central heating systems and, under certain conditions, initial installation costs.
- ✓ Replacement Windows: Replacement of window frames in essential rooms.

Education –

- ✓ Fees: Advanced education course fees where no help is available from the LEA.
- ✓ Special Costs: For specialist equipment or materials, or for 'Field Trips' but not for recreational school trips.
- ✓ School Costs: School clothes, books etc. when a child starts or changes school.

Bereavement –

- ✓ Immediate Payment: To provide readily available cash to help with the extra costs arising at the time of bereavement.
- ✓ Further Payment: Where a person has been nursed at home during terminal stages of illness, a payment may be made towards the cost of replacement of damaged bedding, furnishings etc.

HOW TO APPLY FOR HELP

Grants are normally given for health related needs only. In an emergency, or if you need advice on what is possible, please telephone the office between 9.00 am and 5.00 pm any weekday.

Routine applications should be made in writing and will need to be supported by a recommendation from a member of your Centre staff team (haemophilia, HIV or hepatitis centre as appropriate) and it is now also possible for applications to be made via the e-mail.

The application should include:

- name and registrant number (or DOB)
- why you need help
- what you need
- how much it will cost.

Please remember the following general points:

- **We are likely to be able to deal more quickly with your request if you have been specific about what you need and have included accurate costings.**
- **We usually require two estimates or quotes for work to be done.**
- **Remember, you can telephone us if you find writing letters or filling in forms difficult and cannot ask anybody to help you.**
- **We would like to emphasise that if any need can be met from public sources (e.g. Community Care Grants, Disabled Facilities Grants, home adaptations, special equipment etc.), these sources must normally be tried first. If the official response is inadequate or involves unacceptable delay the Trust may then help.**
- **Emphasis on health related grants means that Trustees will normally need to see an up-to-date doctor's report. Therefore, upon receipt of an application you will be sent a Consent form to complete and return to the office. This will be forwarded to your**

doctor so that confidential medical information about you may be released to the Trust. If it is possible for you to obtain the relevant medical report and supporting letter these can be sent in with your application, which would speed up the process.

- **Widows/partners, dependant children and other dependants will not normally need their application to be supported by a doctor's report. However, a supporting letter from a social worker or other professional can be useful and when necessary will be sought.**

How we handle requests for help

All requests will be acknowledged within five working days and payments made within five days of receipt of all paperwork, unless the request is to be referred to Trustees.

Our reply to you will:

- deal fully with the request if it is within the authority of the staff, or
- request further information if needed, or ask your permission to consult your doctor, or
- tell you when the request will be submitted to Trustees and when you can expect a full reply.

The Trustees meet four times a year in full session. In addition, Allocations Committee Meetings are held at regular intervals to discuss registrant's requests. These meetings are normally held every three to four weeks, but emergency requests may call for a special meeting to be convened.

We are now required to request and keep receipts for work, items or services purchased that cost £250 or more and your cooperation on this matter would be appreciated.

HELP & ADVICE

ADVICE AND INFORMATION FROM THE TRUST

FINANCE (GENERAL)

The staff and Trustees are not legally permitted to give specific financial advice. However, the Trust can recommend an Independent Financial Adviser, who is registered with the Personal Investment Authority and is empowered to give such advice. If consultation with the Adviser requires the payment of a fee, the Trust will normally pay this provided that prior approval for the consultation has been given. The Adviser understands the need for confidentiality in all matters respecting those registered with the Trust.

MORTGAGES

Although it is not possible to guarantee that everyone can buy their own home, to buy is far more possible than was previously thought, and many people have been successful with and without our help. At least it can be said that being HIV positive is not in itself a bar to obtaining a mortgage, though it is a bar to obtaining mortgage protection by way of Life Insurance.

Limited mortgage protection might still be possible by taking out the life insurance policy assigned to your mortgage in your partner's name only. In many cases, however, one of the other forms of mortgage (capital repayment or interest only) could be the best option.

If you or your partner are working you could probably get a mortgage from your bank or a local building society, but you may find it easier or more confidential to use the services of an independent financial adviser.

Even if you are living on benefits it may still be possible to obtain a mortgage, and in fact many of the mortgages arranged in this way facilitated by the Trust have been for people in this situation.

The Independent Financial Adviser has experience of arranging mortgages for a large number of people registered with the Trust. Because negotiations are centrally with the Building Society, you would not have to discuss your affairs in your local branch office.

Capital Costs

Whilst we can help a lot in arranging a mortgage, and will in some cases help with the incidental cost of fees and charges, the Trust will not contribute to the capital cost of house purchase. Home ownership is a form of investment and is a personal choice rather than a need, because ownership is not the only means of providing a home. The Trust will always help you decide which option it is best to pursue in your case, taking into consideration what help the Trust can offer.

Repossession

If anyone is in danger of repossession due to problems with an existing mortgage, the Trust will help negotiate a solution which we hope could provide for continued occupancy. There are several options available to achieve this but we need to discuss each particular case with the persons concerned.

Housing

We can help with advice or by direct action on your behalf, if you have problems with:

- obtaining Local Authority housing
- your housing costs (rent or mortgage)
- landlords (public or private) failing in their responsibilities to maintain your home
- the suitability of your home to meet your needs due to sickness or disability.

With the last problem we may also be able to help financially if the official help is inadequate or is unacceptably slow. (see page 7)

Benefit

The Trust Office has helped many people to take advantage of various benefits. The extra amounts obtained in this way have been a considerable help to those involved. This has been achieved not only by giving information and advice, but especially by direct negotiations with the various authorities on behalf of the individuals concerned, and by representation at tribunals.

This service is always on offer. On pages 14-19 we give basic information about all

benefits to which you may be entitled. With this information you may feel confident to make an application for yourself, but please do telephone for further advice if you need it. In particular if you are having problems or, if for any reason you would like us to handle your case, please call the office.

Investment

If you are intent on investing or reinvesting capital it is our strong recommendation that you seek independent financial advice. The Trust can help you get it.

The advice is completely impartial and, if after you have received it you are charged a fee, the Trust will normally meet the cost if the consultation has taken place with the prior approval of the Trust. The adviser is registered with the Personal Investment Authority.

A general point to be made is that it is not necessarily a good idea to use capital to pay off all or part of an outstanding mortgage. This is because you could be receiving interest on your invested capital while the interest payable on the mortgage could be paid (now or later) by the DWP through Income Support. This is a fairly complex decision so please consult us before taking any action.

Financial Problems

Financial problems do not get better if ignored. Almost invariably they get worse. If you already have, or can foresee, a problem please consult us early. This applies whether the problem appears to be short-term or long-term.

We can help you to examine both your income and outgoings. We may be able to suggest ways of increasing your income and would certainly ensure that you were receiving all possible benefits and help from the Trust. We can also suggest ways of off-loading or spreading your outgoing commitments.

Debts

The Trust will not normally repay debts but it will give all possible help to find a solution, including paying fees of a debt counsellor or accountant if appropriate.

Loans

The Trust is not empowered to make loans and, for that reason, it cannot lend venture capital for businesses or other entrepreneurial projects.

Advances of Regular Payment

Where there is an urgent need for cash but where the Trust cannot agree to make a grant, an advance of regular payment may be possible. Normally we would not reduce the monthly payment below £100 nor advance more than six months of the balance. This is available only for genuine unavoidable expense and not for 'optional' purchases and would not normally be considered again in less than a year from repayment of a previous advance.

HEALTH

One of the Trustees is always a Haemophilia Centre Director and currently another of the Trustee has more than 20 years experience of working in a Haemophilia Centre, so the Trustees have first hand expert advice on medical matters concerning haemophilia and HIV.

The Trust recommends the Treatment Update published by the National AIDS Manual (NAM) (see page 23) as an excellent source of regular information on general progress of medical treatment relevant to HIV. We also tell you in our Newsletters of other information we think of value, and the Haemophilia Society publishes articles in the HQ.

The HIV & AIDS Treatment Directory, published twice a year by NAM, is immensely detailed but written in an accessible style. This manual incorporates information contained in previous issues of Treatment Update. As well as covering treatments it also has reference chapters on: Symptoms; Medical Tests; Opportunistic Infections and Clinical Trials. If you would like your own copy of this book please telephone the Office.

Please remember that this is all general information and not always relevant to every individual. Your treatment is a matter between you and your own doctor. The

Trust will never advise any specific treatment, only that you should discuss it with your doctor. The more informed you are before doing so, the more you will get out of such a discussion.

LEGAL

There is nobody at the trust who has a legal qualification; however, the Trust's solicitors may be able to provide initial advice or a first consultation and then refer a member on to a Law Firm near their home that has Legal Aid Franchise if continuing legal help is required.

Wills

We strongly urge everyone to make a will. This is the only way you can ensure that your estate (cash, property and personal belongings) goes where you want and not where somebody else decides. Remember especially that a common law partner has no rights to your estate, as a spouse does. You may feel that your spouse or some close relative knows well your wishes and can be relied on to follow them. Even so you need a will to put the power into their hands and to eliminate the prospect of other claims or a challenge.

You can write your own will (see advice references on page 23). However, particularly where property is part of your estate or where a partnership is based on common law rather than legal marriage, it would be wise to use a solicitor to prepare the will. We can help with the costs.

Unless affairs are very complex or you want to create a long-term Trust it is best to keep the execution of the will in the hands of family or friends. Remember that beneficiaries can be executors of a will; it is only as witnesses to the signature that they are barred.

Your executors can employ solicitors to do the technical work if necessary, but will retain full control to make the decisions and limit the costs. Some solicitors make things more complicated than they need to be. Be cautious about appointing a bank as executor, as their charges tend to be higher than elsewhere. If you have made a will, do review it every year or so to be sure it still meets your wishes. You do not have to go

back to 'square one' for every small change as these can be covered by a codicil (amendment).

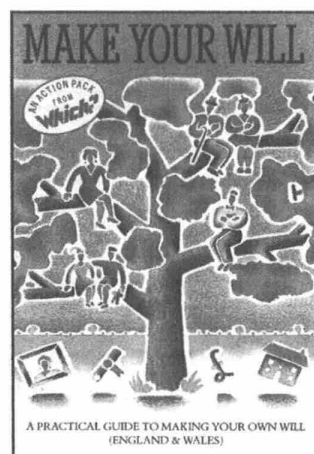
Administration of Estates

When someone dies, his/her affairs must be dealt with by a personal representative (otherwise known as executor or administrator) who will have to apply to prove the will or, if there is no will, apply for a grant of administration. In either case, contact the local Probate

Registry Office (see your local telephone directory) and obtain Form PA2 (How to obtain Probate), which tells you what to do if you have decided not to employ a solicitor.

If there is a will, administration of the affairs of a deceased person is relatively straightforward. We can advise on the technicalities and the executor(s) can decide whether or not to use solicitors to handle the Probate and other actions.

If there is no will it is normally the next of kin or other close family member who should apply for the grant of administration. This is a relatively simple process which they could handle themselves and, if there are no complications, could be completed inside a month. Once the grant is approved, the personal representative has the same powers and responsibilities as the executor of a will, but until then no one has any power at all to do anything with the estate. Again we suggest a call to us to discuss the situation.



Further details about this will-making guide and others can be found on pages 27.

TRUSTEES & STAFF

TRUSTEES

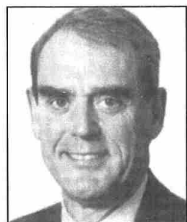
Chris Hodgson - 1992



Chris has **GRO-A** and has been involved with the Haemophilia Society (local and national) for many years. He was elected Chairman of the Haemophilia Society in July 1997 and is co-chairman of the Haemophilia Alliance. Chris

completed a counselling course in 1996 and has been awarded a Certificate in Counselling from the University of Surrey. He is married with two sons and lives in Hampshire.

Peter Stevens 1999



Peter is the father **GRO-A** (and a grand-father); **GRO-A** **GRO-A** **GRO-A** **GRO-A** He has

retired from a major international insurance broking firm. This is his second spell as a Trustee

nominated by the Haemophilia Society, having originally served from 1989 to 1992.

Mark Winter - 1996



Mark is a Consultant Haematologist and Director of the Comprehensive Care Haemophilia Centre in Canterbury. For a number of years, he was the designated district AIDS physician and maintains an active clinical and research interest in HIV

related issues. He serves on the HIV Working Party of the Haemophilia Centre Directors Organisation and is also co-chairman of the Haemophilia Alliance.

Elizabeth Boyd - 2000



Elizabeth has worked in the Haemophilia Centre at the Royal Free Hospital in Hampstead since 1979. Since 1985, she has been the Welfare Rights Adviser at the Centre. Elizabeth is married with two sons and a granddaughter.

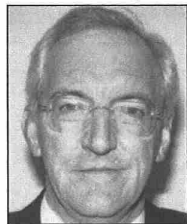
Tony Yeaman - 2000



Tony is a solicitor and partner in the national law firm of Beachcroft Wansbrough. His 22 year career in law has spanned general private practise, industry and the NHS. The last 13 years have been spent advising on all aspects of Health Service law and patient related

issues. He lives in **GRO-C**

Patrick Spellman - 2002



Patrick retired from the DofH as a Senior Civil Servant in 1999. He was with the Ministry of Labour and then the DHSS in the North of England and the London headquarters in the early 70s. In the 80s he was a senior training officer and also spent a number of years on policies for infertility and surrogacy. During the 90s he was involved in research. He lives with his wife and has one daughter who is a research doctor.

Roger Tyrrell - 2002



Roger joined the DofH in 1967 and was Statutory Auditor for a couple of health regions. In 1986 he volunteered to join the AIDS Unit heading up the national and local HIV prevention effort. He became head of unit in 1991 before moving on to head up

disabilities and community mental health policy. He took retirement in 2001 and is now studying counselling and psychotherapy.

Tracey Morgan - 2003



Tracey works as a data analyst at the Office for National Statistics (Newport Office). She has been with her partner for 2 years and hopes to get married at the end of the year. Her main hobby is football and she is an avid Cardiff City supporter as well as

supporting her local team, Abertillery Bluebirds, which is looked after by her partner who is their secretary.

Stuart Gregg - 2003



Stuart is a **GRO-A** **GRO-A**

GRO-A He has recently completed an MA in Social Research at Birmingham University and plans to undertake further research into HIV in the haemophilia community. Stuart

has a partner of 8 years and lives in Worcestershire. His main interests are cycling, swimming, walking his dogs, reading and music etc. Recent achievements include joining MENSEA and sky diving.

STAFF – and who does what

We are a small close-knit team and all work together to provide the best all-round support to you all. Our duties are not in water-tight compartments, but in general:

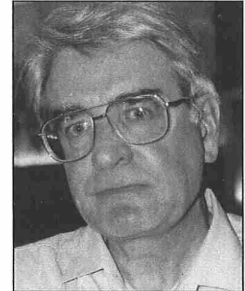
- Ann is Chief Executive and Secretary to the Trustees. She is responsible to the Trustees for policy, financial and legal affairs and for day to day liaison with the Department of Health, The Haemophilia Society and other bodies.
- Rodney is our Finance Officer. He is responsible for the day to day financial operations of the Trust including processing of all payments to registrants and recording and reporting of all financial matters to Trustees and others.
- Claudette is our Social Worker and is responsible for all types of help and advice to registrants. She can answer queries about Trust payments and provide advice and help about most aspects of living with HIV. Claudette is in regular contact with Haemophilia Centres and The Society, and can contact Local Authorities and other bodies on your behalf.
- Carol is our Benefits Advisor. She deals with queries about Social Security benefits and can help sort out problems with the DWP (or with the local council where Housing or Council Tax benefits are concerned). She will also help with appeals against unsatisfactory decisions and attend appeal hearings with you if necessary.
- Roz is our Administrative Secretary, responsible for keeping all our records up to date, acknowledging grant applications and assisting Claudette in preparing grant applications for Trustees and despatching payments to you all.
- Lisa is our Finance Assistance. She helps Rodney with all financial matters and may help him respond to your payment queries.

Carol, Claudette and Ann regularly confer together to try to develop the best all-round support for any request for help, and to ensure that our response is consistent from one request to another.

Ann - 1997



Rodney - 1999



Claudette - 2000



Roz - 2000



Carol - 2001



Lisa - 2002



WELFARE BENEFITS

WELFARE BENEFITS

Please see below for details of the benefits you are likely to be able to claim. If you need more detailed information, or information on any benefits not covered here, the Benefits Advisor is generally at the Trust on Tuesdays, Thursdays and some Fridays and will also do home visits. Otherwise, at the end of this section there is a list of advice agencies and publications.

The list of benefit rates has been reduced. The list now only includes those benefits where it is straightforward to check entitlement, but not those where benefit entitlement involves a calculation (for example, Housing Benefit and the tax credits), as the figures alone are no use without the calculation details. If you are considering claiming one of these benefits and need to know the amount involved, the Benefits Adviser will willingly do a calculation.

Working/not working

Many of the enquiries received concern members either thinking of starting work or having to give up work. If you are giving up work and claiming benefit, there are 2 options:

Jobseekers Allowance (JSA)

You have to sign on as available for and actively seeking work. You will get 'contribution-based' JSA for 6 months, if you have an adequate National Insurance contribution record. Otherwise, you get means-tested JSA. If the amount of contribution-based JSA is less than the amount of means-tested JSA (for example, you have a partner, children or a

mortgage), you will get a top-up to the means-tested level. However, it is usually more advantageous to claim.

Incapacity Benefit (IB)

IB is paid when you are not fit enough to work. It too is based on NI contributions and at present is not means-tested except in the cases of some claimants who receive personal, occupational or public service pensions. IB increases after 6 months and again after 12 months, unlike JSA, and there are additions for partners and children, as well as age additions.

If you find yourself out of work, you should consider carefully whether to make a claim on the basis of 'unemployment' or 'incapacity'. The advantages of the 'incapacity' route are:

- You don't have to sign on
- Your benefit doesn't run out after 6 months
- You start the clock ticking for higher rate long-term Incapacity Benefit immediately
- you will not have to enter into a Jobseekers Agreement about looking for work
- because of changes to the rules about contribution conditions it will be more difficult to transfer to IB following a period of JSA.

To be paid IB, you must pass the 'personal capacity assessment' or be deemed incapable and, therefore, exempt. See 'Personal Capability Assessment'.

Severe Disablement Allowance (SDA)

This used to be the alternative to IB for young people who did not fulfil the conditions for claiming IB (generally because they did not have any/enough NI contributions) but who had become incapable of work in youth. SDA has now been abolished for all new claims. However, now people who become incapable of work in youth will be able to claim IB even though they do not have any/enough NI contributions, as long as they fulfil all the other relevant conditions. If you are a young person who has become incapable of work before the age of 20, or you have been studying and have become incapable of work before the age of 25, you should consider applying for IB. Rules for claiming IB under these circumstances are complex and you should obtain advice if you believe that you may be entitled under the above rules.

The other benefits you might be able to claim are means-tested. The main one of these is:

Income Support

There is a government set level of income for any household, which allows for size of family, age, disability and caring responsibilities. If your actual income falls below this level, the difference is made up by Income Support. It is payable to pensioners, carers, lone parents and people whose other benefits fall below the level.

Other Means-Tested Benefits

Working Tax Credit (WTC)

You can claim WTC if you work at least 16 hours a week and are on a low income. There is no capital limit, but income from capital will be taken into account. The amount of benefit depends on: number of

adults in the family, exact number of hours worked per week, age of worker, childcare costs and disability in the family. It is paid either by your employer or by the Inland Revenue.

Child Tax Credit

You can claim CTC if you are aged 16 or over, responsible for a child and on a low income. The amount of benefit depends on: age of children and disability in the family. 90% of families should be entitled to this benefit.

Help With Housing Costs

Housing Benefit (HB)

If you are on a low income, you may get help with your rent by claiming Housing Benefit. This is paid by the local authority. If you are receiving Income Support, you will generally get full Housing Benefit. However, you can still get help if you are above the IS level. Housing Benefit can be claimed by either private or council tenants, and whether you are working or not. There may be restrictions on the amount of rent met because of the size of your accommodation. If the amount of Housing Benefit you get is reduced because of this you have a right to appeal.

Council Tax Benefit

This provides help towards your Council Tax bill and is claimed in the same way as Housing Benefit. It can be claimed by owner-occupiers and tenants. Anyone living alone automatically qualifies for a 25% discount. (This does not in itself entitle you to a higher regular payment from the Trust). If you have had substantial alterations made to your home to accommodate the needs of a disabled person, you move down to a lower band for Council Tax (i.e. a smaller bill).

Mortgage Interest

If you are on Income Support and an owner-occupier, you may get all or part of your mortgage interest met by the DSS. However, no help is given with the capital repayment part of a mortgage, nor with any insurance premiums connected with it.

Income Support only covers interest on a loan taken out to buy your home (or a previous loan taken out for the same purpose). Interest on a loan taken out for certain essential repairs or to adapt your home to make it more suitable in view of your disability is also covered.

Taking Out a Mortgage While on Income Support

Generally speaking, if you take out a mortgage while on Income Support you will not get your mortgage interest met. However, if you take out a loan to buy 'alternative accommodation more suited to the special needs of a disabled person' you will not be caught by this rule.

A move to be nearer a carer or source of care such as your haemophilia centre is acceptable. A move to a more suitable property is also acceptable e.g. from a house to a bungalow.

If you take on a mortgage while on IS and you were previously getting Housing Benefit, you can get help with your mortgage interest but it will be restricted to the amount of Housing Benefit you were getting (this does not apply if you are changing your mortgage for 'disability' reasons).

Standard Rate of Interest

To calculate the amount of interest to be met, the Benefits Agency contacts your bank or building society to establish the capital outstanding on your mortgage. For an interest only or endowment mortgage, this figure will remain the same for the

entire term of your mortgage. With a repayment mortgage this figure reduces over time and, therefore, the DSS contacts your lender on an annual basis for an outstanding balance figure. In calculating the interest payable, the DSS uses a standard rate of interest and not the actual rate charged by your lender. The standard rate of interest 'tracks' the variable interest rate of the top twenty building societies. In practice, this means that when interest rates are rising claimants are a little better off. On the other hand, whilst rates are in decline claimants can be a little worse off due to the time lag.

Mortgage Ceiling

On 2nd August 1993, a 'mortgage ceiling' was introduced. Since this date, interest has only been met on the part of your loan up to the prevailing ceiling. Since 9th August 1995, the ceiling has been £100,000. You should bear this in figure in mind if you are on IS and thinking of taking out a mortgage. This ceiling will also affect anyone with a mortgage higher than £100,000 who has to give up work due to ill health and consequently has to make a claim for IS. Additional loans taken out to adapt your home because of your disability, are not affected by this limit.

Waiting Periods

Depending on when you took out your mortgage, the DSS will impose one of two waiting periods (this does not apply to people aged 60 or over). If you took out your mortgage after 2nd October 1995, you will not get any help with mortgage interest for 39 weeks. If you took out your mortgage before this date, a less stringent waiting period is applied as follows:

- first 8 weeks - no help
- week 9 to week 26 - only half your

mortgage interest is included in the IS calculation

- after 26 weeks all of your mortgage interest is included

If, when you take out a mortgage you have been on IS for 26 (or 39) weeks, your mortgage interest should be included immediately. The DSS often overlooks this fact and tries to impose a waiting period when it shouldn't.

Health Related Benefits

Disability Living Allowance (DLA)

This is a very important benefit for people with health problems. Most members receive the mobility component and many receive the care component as well. There are many advantages to claiming:

- it is not means-tested and is paid in addition to any other income you may have you can claim it even if you are working
- it can entitle you to a higher level of means-tested benefits (such as Income Support) or even help you to qualify if you have not done previously
- the higher rate of the mobility component gives access to the Motability scheme and the blue badge scheme, and exemption from road tax
- it does not depend on your national insurance record
- your carer may be able to claim a benefit in their own right

DLA consists of two components, each paid at different levels. You can get either one or both components at different levels. There are eleven different combinations.

Mobility Component

This is paid if you have problems with walking or if walking poses a danger to your health. You don't have to be completely unable to walk in order to qualify. People with severe haemophilia get it by providing evidence that the bleeds into knee and ankle joints can, over time, cause a serious deterioration in their health. The component is, therefore, awarded as a preventative measure and not only because of existing joint damage. If you have mild haemophilia, it will be difficult to argue your case on these grounds. You need, therefore, to emphasise any other mobility problems caused by your HIV (tiredness, breathlessness etc).

Care Component

This is paid if you establish that you need care and/or supervision during the day and/or night on more days than not. You do not have to be getting care already to qualify and, once benefit is awarded, you are under no obligation to use it to employ a carer.

When you complete the care section of the DLA form you should cover:

- fatigue, particularly if it prevents you from performing tasks associated with daily living (cooking a meal, washing, dressing etc.)
- night sweats or other problems at night
- dizzy spells or blackouts
- incontinence or diarrhoea
- depression or other psychological problems, particularly if this means you have to be 'prompted' to get up, wash, dress, etc.
- problems other than mobility associated with joint damage caused by your haemophilia (problems with dressing, using the bath etc.)

Carer's Allowance (CA)

You can claim this if you are caring for someone who gets the high or middle rate of DLA care component. You (the carer) must be earning less than £77 per week and not in full-time education. It makes no difference if the person you care for is working.

If you are getting IS, the amount of CA is taken off your Income Support. You do, however, get an additional premium added onto your IS (the carer's premium) so it is worth claiming. There have been several cases where the Benefits Agency have advised people not to claim CA as it will be taken off your IS - generally, ignore this advice.

There is only one situation where it is better not to claim and that is where the person you care for lives alone and gets IS. In this case, they get an addition on their own IS (the severe disability premium), which they lose if you claim as their carer. If in doubt, seek advice.

Personal Capability Assessment

This replaced the 'all work test' in April 2000. The intention is still to provide an objective assessment of the extent to which your illness or disability reduces your physical or mental ability to work. When it is fully up and running, it will also involve a DSS doctor preparing a 'capability' report, as well as the present incapacity test. This will provide advice on personal capabilities and the possibility of rehabilitation.

Many people are exempt from the 'personal capability assessment'. You will be exempt if:

- you get the highest rate care component of DLA
- you are terminally ill and your death can 'reasonably be expected within 6 months'

- you are registered blind
- you have: tetraplegia; persistent vegetative state; dementia paraplegia or 'uncontrollable involuntary movements or ataxia, which effectively renders you functionally paraplegic'

You are also exempt if a DSS doctor certifies that you have:

'Manifestations of severe and progressive immune deficiency states characterised by the occurrence of severe constitutional disease, opportunistic infections and/or tumor formation'.

The DSS has issued its doctor with guidance, which suggests that you will be regarded as having 'severe constitutional disease' if over 1-2 months you have symptoms such as:

- loss of 5-10% of normal body weight, or
- fever/night sweats, or
- increasing overactivity of the bowels, or
- 'CD4 count' less than 500

The assessment also applies to people who are getting a means-tested benefit claimed on the basis of incapacity. Housing Benefit and Council Tax Benefit may also be subject to this test where a person's assessment has included the disability premium.

Special Rules

An alternative to completing the DLA claim form is to apply under 'special rules'. These rules allow anyone who may have less than 6 months to live to apply without needing to establish care needs. If you decide to claim under the special rules,

your doctor will have to complete a form DS1500. On this form, he provides the DSS with information about your diagnosis and treatment but he is not expected to state your life expectancy.

In the majority of cases, those who are awarded DLA under 'special rules' are by no means likely to die within 6 months. When making a claim for DLA care, you should discuss the possibility of a 'special rules' application with your doctor as this may be the most effective and least complicated way of making a claim. Claims are dealt with within 15 days and claimants are automatically awarded DLA high rate care.

If you make a claim under 'special rules' and are already in receipt of some component of DLA, your claim will be dealt with as a super-session. The rules which apply to super-sessions, allow adjudication officers to backdate the awards for 1 month before the date of completion of DS1500's. Sometimes the Disability Benefits Centre dealing with your claim will do the backdating automatically, but more usually you will have to ask for it. You can do this either when making the application or when you are notified of your award.

Bereavement Benefits

Bereavement benefits were introduced on 9th April 2001. They replace the old system of Widow's Benefits and can be claimed by both men and women whose spouse died on or after 9th April 2001. In addition, if you are a man whose wife died before 9th April 2001, you may qualify for WPA although you cannot qualify for BP or BA. If you are a woman whose spouse died before 9th April 2001, you may still qualify for Widow's Benefits.

Bereavement benefits are based on your late spouse's contribution record. The present rules are set out below:

Bereavement Payment (BP)

This is a tax-free lump sum payment of £2,000 paid to widowers/ widows under pension age when their spouse died. You must claim within 3 months of your spouse's death.

Widowed Parents Allowance (WPA)

This is a taxable weekly benefit for widows/widowers with dependant children (i.e. entitled to Child Benefit). It is made up of a basic rate payment and addition for each qualifying child.

Bereavement Allowance (BA)

This is a taxable weekly benefit for widows/widowers who are 45 or over but, under pensionable age when their spouse died. It is payable for 52 weeks. You cannot receive WPA and BA at the same time, but you may qualify for BA when you stop being entitled to WPA.

Widows/widowers who don't qualify for WPA or BA should consider applying for Income Support or Job Seeker's Allowance.

Changes

These will not affect anyone who is already receiving these benefits.

The Social Fund

Funeral Grants

You are entitled to a funeral grant if:

- you or your partner get IS, Income-based JSA, WFTC, DPTC, HB, or CTB at the time of your claim, and

- you accept responsibility for the costs of the funeral

The grant covers the basic costs of documentation, cremation fees and transport with an additional £600 for 'other expenses'. Insurance, other available assets and charitable payments are deducted from the award. However, any payment from The Macfarlane Trust or Eileen Trust is not deducted from the award.

There is priority order for deciding who is to be treated as 'responsible' for the funeral. The 'responsible person' will be the surviving partner or, where there is no partner, a close relative. A close friend will be accepted as 'responsible' where there is no partner and it is reasonable that s/he, rather than a relation, should take responsibility.

Community Care Grants

These can be applied for by anyone who receives IS. Remember you do not have to declare any payments you may be getting from the Trusts. Grants are discretionary and dependant on local budgets. These are the sort of items we have successfully claimed for:

- washing machine
- tumble drier
- cooker
- heater
- clothing and footwear (especially for severe weight loss or gain)
- carpets, furnishings e.g. curtains & chairs
- special furniture for disabled/elderly
- redecorating costs
- removal costs for setting up/moving home

- minor house repairs
- draught-proofing
- safety gates, fire guards and other safety equipment
- travel costs

Hints on Claiming

The purpose of making these grants (as opposed to repayable loans) is to enable people to continue living in the community.

In addition, a system of priority groups operates - one such group includes families who are trying to cope with difficult problems such as disability or long-term illness and who are, therefore, under exceptional pressure. If you can show that a grant will help you to cope and avoid the risk of being taken into residential care, that you are on IS and belong to a priority group, you should apply. The risk of being admitted to 'care' does not need to be immediate; you just need to show it could be a possibility if your needs are not met. Include as much supporting information as possible from a Social Worker or Centre Doctor. Make claims on form SF300 available from your local DSS office or from the Trust.

We regularly help members to claim SF grants when moving or setting up home for the first time. Payments average around £1,000. There have also been numerous smaller awards for items such as cookers and carpets that the Trust does not automatically help with.

Underclaiming & Other Problem Areas

Due to the complexity of the Income Support regulations, there is widespread underclaiming. The main problem areas encountered by Trust members are outlined below:

Full-time Education

Many members in full-time education are not claiming the IS to which they are entitled.

If you are 16 to 18 years old, following a course up to and including A level and lasting more than 12 hours a week and you get DLA (mobility and/or care components) you stand a very good chance of getting IS. This could be as much as £65-£70 a week, although your parents will lose the Child Benefit paid for you and any IS that they receive for you.

If you are at college following a full-time higher level course (above A level standard) and getting DLA (mobility and/or care component) you can claim IS. You will be treated as having taken out a loan whether or not you have, and an amount less allowances for books and travelling will be deducted from your Income Support. Given the very low level of student grants, this still represents a worthwhile increase in net income.

Although IS rules (which apply to sixth formers and college students) are not very complicated, it is our experience that DSS officers need to be gently persuaded that they are allowed to pay IS under these circumstances. If you would like us to help you claim IS, please contact the Trust.

Recoveries from Estates

When an IS claimant without dependants dies, the DSS Recoveries Section checks with the District Probate Registry for the existence of an estate. If an estate in excess of the IS capital limit is discovered, an overpayment is assumed and steps are taken to make a recovery from the estate. Where the estate consists solely of Macfarlane Trust payments, the DSS should not proceed with its recovery action. Unfortunately, the DSS has no way of discovering the source of a person's capital in advance in order to avoid distress to the

deceased person's family. Where a recovery is being undertaken inappropriately, the Trust will intervene and provide the DSS with payment details to establish beyond doubt the source of capital.

Tips on Claiming Benefits

- Always keep copies of any forms you send to the Department of Social Security (DSS). If you are concerned about photocopying costs, send them to us and we will make copies free of charge and retain them on your file in case of any problems later on with your claim.
- If in doubt, claim! We know of many members who have been reluctant to claim for fear of being turned down, but who have been pleasantly surprised at the ease with which a successful claim has been made.
- Seek advice at once if you are not happy with a decision. Time limits for appeals have been reduced from 3 months to 1 month, so it is essential to act quickly.
- Get people to support you. Claims for DLA and Social Fund Community Care grants are far more likely to succeed if you obtain the backing of a 'professional' such as your Centre Doctor, Social Worker or the Benefits Adviser at the Trust.
- If you telephone the Benefits Agency, always get the name and extension number of the person you speak to. All DSS officers are obliged to give you their name. Ask for the section supervisor or customer care officer if you are not happy with the way your claim is being handled.
- Backdated claims - always seek maximum backdating of benefits but be

prepared to provide good reason for making a late claim. DLA cannot normally be backdated but some benefits can be backdated for up to 3 months.

- Confidentiality - for some benefits you do not need to mention your health but for others such as DLA and IB it is vital that you provide as much information as possible including your HIV and HCV status. All DSS officers are bound by strict confidentiality rules (we know of no case where these have been breached).
- Method of payment - ask to be paid direct into your bank or building society account. This way you will be paid promptly without having to worry about a payments book, or collecting the benefit from the post office.
- If your benefit application is turned down or if you get a lower award of DLA than you feel is appropriate, you may have a right of appeal; the letter turning you down should tell you this. If you do have the right, it is well worth making an appeal as a high percentage of decisions are changed in this way.
- Get help completing the DLA claim form. The form consists of 40 pages asking detailed questions about problems you have in managing your daily life and the help you need. It is not easy to describe the problems arising from conditions, which fluctuate and vary and it can be depressing to concentrate on all the negatives, but it is essential that this is all included and described fully.

are intricate and a common source of underpayment mistakes. In particular, there are certain people who could be living with you but not counted, so you could still be treated as living alone. Seek advice if you think you are missing out on this premium.

Severe Disability Premium (SDP) - Income Support

This premium can be allowed on top of the ordinary disability premium if you get the DLA care at the higher or middle rate and live on your own. You won't get this premium if someone gets ICA for looking after you. The rules which apply to SDP

WELFARE BENEFITS 2003

MEANS-TESTED BENEFITS

Income Support/Non-contributory Job Seeker's Allowance

Personal allowances

single	
under age 18	£32.90/£43.25
aged 18-24	£43.25
aged 25 and over	£54.65
lone parent	
under age 18	£32.90/£43.25
aged 18 or over	£54.65
couple	
one or both under age 18	£65.30
at least one aged 18 or over	£85.75
dependant children	
to Sept after 16th birthday	£38.50
from Sept after 16th birthday to day before 19th birthday	£38.50

Premiums

family	£15.75
pensioner	
single	£47.45
couple	£70.05
disability	
single	£23.30
couple	£33.25
enhanced disability	
single	£11.40
couple	£16.45
child	£16.60
severe disability	
per qualifying person	£42.95
disabled child	£41.30
carer	£25.10
bereavement	£22.80

Capital limit

disregarded	£3,000
tariff income on capital between £3,000 and £8,000 -£1 for every £250 or part thereof	
upper limit	£8,000
child's limit	£3,000

Contributory Job Seekers Allowance

single	
under age 18	£32.90
aged 18-24	£43.25
aged 25 and over	£54.65

NON-MEANS-TESTED BENEFITS

Attendance Allowance

higher rate	£57.20
lower rate	£38.30

Child Benefit

only, elder or eldest child	£16.05
each subsequent child	£10.75

Disability Living Allowance

Care component

higher	£57.20
middle	£38.30
lower	£15.15

Mobility component

higher	£39.95
lower	£15.15

Earnings rule

Carer's allowance	£77.00
Permitted work earnings limit	£67.50

Carer's Allowance

increase for adult dependant	£43.15
	£25.80

Incapacity Benefit

short-term (under pension age)

lower rate	£54.40
higher rate	£64.35

short-term (over pension age)

lower rate	£69.20
higher rate	£72.15
short-term adult dependant	£41.50
long term	£72.15
long-term adult dependant	£43.15

increase of long-term for age

higher rate	£ 7.60
lower rate	£15.15

Retirement (category A&B) and widow's pension, widowed mother's allowance, bereavement allowance and widowed parents allowance

single person	£77.45
adult dependant/wife (retirement)	£46.35

Severe Disablement Allowance

adult dependant	£43.60
age related addition	
higher rate	£15.15
middle rate	£ 9.70
lower rate	£ 4.85

Statutory Sick Pay

standard rate	£64.35
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IMPROVING THE TRUST'S SERVICE

In 2003, to mark the 15th year since the Macfarlane Trust was established, a Long Term Review is being carried out to help Trustees plan and prioritise how the Trust's resources can be used most effectively for all its beneficiaries over the next five years. The Review will include the use of an anonymous questionnaire, focus groups and other ways to find out as much as possible about people's needs and aspirations. The Review carried out in 1998 resulted in significant uplifts to monthly payments and single grants and increased annual expenditure by 50%. This time Trustees will not be considering ways to increase Trust payments as a result of the Long Term Review but rather to make more effective use of the funds received from The Department of Health.

COMMENTS AND SUGGESTION

If you have any comments on Trust policies or the way they are carried out, or suggestions for improvement, please make them known to us. Anything you write or say will be put to the Trustees and you will be sent a reply. All comments and suggestions will be seriously considered, and if they would lead to improvement, will be implemented if at all possible.

The Trustees have to determine priorities and allow for the future, so that improvements cannot always be afforded. In particular, a change which would only benefit a small minority would have to be balanced against its effect on the majority.

Even if your suggestion is not taken up at once it will not have been a waste of your time. What may now not be possible, may become so later. The Trustees aim to allow for changing needs and not to be tied to previous decisions.

REVIEW OF REJECTED APPLICATIONS

The procedure to request a review is explained on page 4.

COMPLAINTS

A complaint may arise if you are dissatisfied with the way you have been treated by the Trust or by a particular individual. For example you might consider that we have taken too long in giving a decision, that we have not been courteous in writing or speaking to you, or that you have not been treated fairly.

A complaint should be made in writing to the Chairman of Trustees. It should refer to a specific incident or series of incidents and should be made by the person registered or the family carer of a minor or of a person who is too unwell to deal with the matter. All complaints will be acknowledged immediately and investigated as quickly as possible. All will receive a full reply from the Chairman when action has been decided.

CONSULTATION WITH TRUSTEES

Trustees value opportunities to meet with members to discuss the affairs and future of the Trust. Invitations and requests from individuals or groups are welcome and Trustees and staff are happy to come and meet members 'on their own patch' or see them at the Trust's office in Central London.

THE PARTNERSHIP GROUP

The Partnership Group was set up in 1999 following a Strategic Review of the Trust. The Group provides a forum for registrants to regularly meet with the Chairman, Chief Executive and other Trustees and staff to discuss relevant issues of policy and practice and work together to improve Trust services. The Group meets four times a year in London and is open to any interested registrant. All expenses related to attending the Group are covered by the Trust.

A USER TRUSTEE

In January 2001 the Haemophilia Society appointed a 'user Trustee' to the Macfarlane Trust Board. Whilst not acting as a 'representative' for registrants, the user Trustee is able to bring a valuable personal perspective to Trust policy and practical issues, thus helping the Board to gain greater understanding of the needs and problems facing registrants.

APPENDIX: OTHER SOURCES OF HELP, AND GENERAL INFORMATION

NATIONAL ADVICE AND SUPPORT ORGANISATIONS

AVERT (AIDS Education & Research Trust)

4 Brighton Road, Horsham, West Sussex, RH13 5BA

Tel: (01403) 210202

E-mail: info@avert.org

Website: www.avert.org

AVERT is a charity entirely funded by voluntary donations whose aim is to prevent people becoming infected with HIV, to work with others to develop a cure and to improve the quality of life for those already infected. It works towards this aim through research and education.

The Birchgrove

Birchgrove, PO Box 9755, Solihull, B92 9WA

Tel: (01476) 581111

E-mail: birchgrove1@hotmail.com

A network of regional support groups set up by HIV positive haemophiliacs, their partners and parents. It aims to give help and support to all those involved with and living with HIV. The Birchgrove produces information sheets and a newsletter.

Blackliners

Unit 46 Eurolink Business Centre, 49 Effra Road, London SW2 1BZ

Tel: 020-7738 7468

E-mail: info@blackliners.org

Blackliners is a counselling, care and support service for people affected by HIV/AIDS who are of African, Caribbean, or Asian descent.

CAB International

Wallingford, OX10 8DE

Tel: (01491) 832111

Website: www.cabi.org

Location for main abstracting services on general international health and disease, including AIDS; publication of Tropical Diseases Bulletin, Abstracts on Hygiene and Communicable Diseases, AIDS Newsletter, Current AIDS Literature, and Public Health News. Administration and subscriptions are also handled from this office.

Child Poverty Action Group

94 White Lion Street, London, N1 9PF

Tel: 020 7837 7979

E-mail: staff@cpag.org.uk

Website: www.cpag.org.uk

CPAG produce rights guides to welfare benefits and other benefits related publications. The public can ring for handbooks.

Children with AIDS Charity (CWAC)

2nd Floor, 111 High Holborn, London WC1V 6JS

Tel: 020 7242 3884

A national charity established to help children infected or affected by HIV/AIDS with the aim of ensuring that these children and their families lead as near normal life as possible.

**CRUSAID Centre
(The Information Exchange)**

Chelsea and Westminster Hospital, 369
Fulham Road, London SW10 9TR
Tel: 020 8746 5929

The Information Exchange, which was opened in November 1994, is the first stage of the CRUSAID Centre. It aims to provide a wide-ranging HIV/AIDS treatments information service, much of which is accessed through computer systems. There is also a range of treatment and newsletters and published resources available. Requests can be made for information on specific topics relating to HIV/AIDS treatments, care and research. The Information Exchange also organises information seminars on relevant topics.

CRUSE Bereavement Care

Cruse House, 126 Sheen Road,
Richmond TW9 1UR
Tel: 020 8332 7227

CRUSE offers to help all bereaved people through its 190 local branches, by providing both individual and group counselling, opportunities for social contact and practical advice. A list of related publications and newsletters is also available.

The Disability Alliance

1st Floor East, Universal House, 89-94
Wentworth Street, London E1 7SA
Tel: 020 7247 8776

Disability Alliance produce rights guides to welfare benefits and other benefits related publications.

The Haemophilia Society

Chesterfield House, Euston Road,
London NW1 3AU
Tel: 020 7380 0600
E-mail: babs@haemophilia.org.uk
Website: www.haemophilia.org.uk
Provides advice, support and assistance to people with haemophilia and their families.

NAM Publications

16A Clapham Common Southside,
London SW4 7AB
Tel: 020 7627 3200

E-mail: claire@ **GRO-C**
Website: www.aidsmap.com

NAM is a charity whose principal aim is to support the fight against HIV and AIDS with relevant, up-to-date, accurate and comprehensive information. NAM publishes the National AIDS Manual and AIDS Treatment Update.

National AIDS Helpline

Network Scotland, The Mews,
57 Ruthven Lane, Glasgow G12 9JQ
Tel: 0800 567123
24 hour national phone-line offering confidential advice, information and referrals on any aspect of HIV/AIDS to anyone.

Pos+Net HIV/AIDS BBS

The Positive Place, 52 Deptford Broadway,
London SE8 4PH
Tel: 020 8695 6655
UK's first Bulletin Board System (BBS) specifically aimed to expand and supply information on HIV and AIDS. Allows individuals or organisations to access and exchange information via a computer and modem.

Positively Women

347-349 City Road, London EC1V 1LR

Tel: 020 7713 0222

Website: www.positivelywomen.org.uk

Positively Women was founded to provide a range of free and strictly confidential counselling and support services to women with AIDS and HIV.

Terrence Higgins Trust

52-54 Grays Inn Road, London WC1X 8JU

Tel: 020 7831 0330

0845 1221200 till 10.00pm

Website: www.tht.org.uk

The Trust's mission is to provide and promote a diversity of radical and effective community based responses to HIV/AIDS through health promotion programmes, services and care, and by influencing society to create a greater understanding of the social impact of HIV/AIDS and the needs of all those affected.

FURTHER READING**Books**

Disability Rights Handbook - The Disability Alliance

National Welfare Benefits Handbook - CPAG

Rights Guide to Non-Means-Tested-Benefits - CPAG

Rights Guide for Home Owners - CPAG

Benefits for People with HIV - The Terrence Higgins Trust

AIDS Reference Manual - NAM

AIDS Directory - NAM

HIV & AIDS Treatments Directory - NAM

Make Your Will - Consumers' Association (order by telephone on 0800 252100)

Will Making Guide - Haemophilia Society

Newsletters and Journals

The Birchgrove - National Birchgrove

AIDS Newsletter - CAB International

AIDS Treatment Update - NAM

Details of organisations listed in this section of the Handbook are taken from the NAM AIDS Directory. The Trust holds a copy of this directory. Should you require information about any other national or local HIV and AIDS organisation please telephone the office.

THE MACFARLANE TRUST

Our service standards

The Macfarlane Trust exists, according to its Trust Deed, "to relieve those who are in need of assistance or the needy spouses, parents, children or other dependants of such persons and the needy spouses, parents, children or other dependants of such persons who have died."

The Trust is committed to providing a confidential, fair and swift service to its registrants and their dependents and will strive to meet the following service standards:

A confidential service

- you can be sure that we will maintain strict standards of security in respect of all personal information held in our files
- we will not without consent disclose any information about registrants or dependents to third parties
- all requests for financial assistance considered by Trustees will be presented on an unidentifiable basis

A fair service

- wherever possible we will assess requests for assistance, financial or otherwise, according to criteria that have been previously established with the health needs of applicants paramount
- if your request falls outside established criteria, the Trustees will assess it objectively and sympathetically, taking advice as necessary from medical practitioners, social workers, occupational therapists, independent financial advisers or other professionals.

A swift service

- we will endeavour always to answer your telephone call in person. Where that is not possible, we will ensure that there will be a means of leaving a message; the first priority of any staff in the office, as soon as they are available, will be to listen to recorded messages and return calls
- we will acknowledge all requests for financial assistance

in writing or by phone within 5 working days of receiving the request

- where decisions on financial assistance can be made without reference to Trustees, payment will be made within 5 working days of receipt of all necessary documents
- where requests for financial assistance need to be considered by Trustees, their decision will be communicated to you within 3 working days of their meeting

How can you help us?

- please respond to requests for further information swiftly and fully
- please let us know about changes in your personal circumstances. They might affect the level of financial assistance we can give and make it difficult for us to keep in touch with you
- please accompany requests for financial assistance with up-to-date medical evidence, if requested; and, where appropriate, at least two estimates of cost
- please return receipts and acknowledgement slips for all successful applications

If you wish to complain that we have failed to meet these standards or about any other aspect of our service:

- you should write to the Chief Executive or the Chairman setting out the circumstances about which you wish to complain. Your complaint will be acknowledged in writing within 5 working days of receipt and will be investigated, quickly, thoroughly and in confidence. You will receive a written response as soon as is possible.
- should you wish to take your complaint further you may ask for it to be reviewed by the whole Trustee Board. This review will take place at the next scheduled meeting of the Trustees, from whom you will receive a response in writing, if possible within 5 working days of that meeting.