

MFT Handbook 2000

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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

Nicholas Lawson ♦ London

Christopher Hodgson ♦ Alresford

Patricia Latimer ♦ Newcastle

Anthony Yeaman ♦ Ropley

Vacant

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

Elizabeth Boyd ♦ London

Dr Mark Winter ♦ Canterbury

Patricia Winterton CBE ♦ Bromley

Vacant

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

2000

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 dependants. This Handbook aims to give information about the help available.

Please read this Handbook carefully. Changes both to the Trust's policies and to the system of welfare benefits available have led to many changes since the last Handbook, so do not be misled by any similarity in its appearance into thinking that its content is the same.

The sections dealing with regular payments from the Trust and with welfare benefits are especially important since they are intended to show you all the income you could be receiving from these sources.

The Trustees have become increasingly aware of the changing needs of people living with HIV infection, and have developed new policies that seek to respond to these changes. These will result in a substantial increase in the rate of expenditure of the Trust's funds, and should, therefore, be noticed by each of you as an increase in the financial support that the Trust provides, especially in the amount of regular payments that you receive.

However, the Trust's funds cannot meet all the financial needs or desires of those we seek to help. While increasing regular payments, the Trustees will need to be more discriminating in responding to requests for single payments, in order not to deplete the funds at an unacceptably fast rate. Single payments will, therefore, be restricted more than in the past to circumstances where health is the over-riding criterion.

The Trust will continue to seek contributions towards meeting requests for financial help from other sources, such as the statutory and voluntary agencies, financial institutions, the Haemophilia Society and others. The section in this Handbook covering financial and other advice available from and through the Trust is most important in showing you that we can do more than just provide monetary assistance.

As before, we have tried to provide the information in this Handbook as clearly as possible. Nevertheless, some of the subject matter is complex, and you should not regard the Handbook as the sole source of information. The staff at the Trust will always be pleased to help you with specific enquiries for which you cannot find all the answers in the following pages. We will also always be happy to consider suggestions about improvements that you feel can be made to the Handbook or, indeed, to any 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 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 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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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.

Since 1990 around 80% of Trust expenditure has been on regular and winter payments. From September 2000, in recognition of views expressed by the great majority of those registered with the Trust, the proportion of Trust expenditure accounted for by regular and winter payments is likely to rise to nearer 90%. How you use these 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 and that this applies particularly at times of acute sickness or bereavement. Single payments are therefore paid to meet this sort of emergency need and only rarely for things which could be regarded as routine living costs.

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.

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 even than those required by the Act. The only time we would discuss your affairs with anyone else would be at your request, if you asked 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

All Trust Payments were reviewed in 1999. In response to demand, Regular Payments have been substantially increased with effect from September 2000.

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 week end 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 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 decided to provide a single lump sum payment, to be made in November. This decision is reviewed each year and notified in a newsletter.

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 cheque will be sent.

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

SINGLE PAYMENTS

Following the Payments Review held in 1999 and the consequent increase to Regular Payments, in future Single Payments to those registered will normally be restricted to health related needs only, and should 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 60% 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 payable to anybody whose circumstances are not described in B or C below	£255
B	For those receiving retirement pensions or benefits other than Income Support or Working Families Tax Credit, or who have children and receive Disabled Persons Tax Credit	
	Standard Rate (as in A)	£255
	plus any or all of the following additions:	
	if receiving Council Tax Benefit	£11
	if receiving Housing Benefit	£22
	for partner	£11
	for each dependant child (to a maximum of 4)	£11 each
	making total payments for those in this category	£255 to £343
C	Higher rates for those who receive Income Support or Working Families Tax Credit, who have children and receive Disabled Persons Tax Credit or who have Student Loans	
	Standard Rate (as in A)	£255
	plus any or all of the following additions:	
	if receiving any of the qualifying allowances listed above (i.e. Income Support, etc)	£50
	for partner	£30
	for first dependant child	£30
	for each other dependant children (to a maximum of 3)	£6 each
	making total payments for those in this category	£305 to £383

For Partner who is HIV positive

Standard Rate	Payable in addition to whatever rate the registered person receives (the registered person will not receive any additional partner's allowance under B or C above if a positive partner receives this payment)	£255
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For Registered Person or Partner who is HIV positive and who receives the Higher or Middle Rate Care Component of Disability Living Allowance (or of Attendance Allowance)

Supplement	Payable in addition to any of the above	£61
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For Widows and Dependants

For six months following bereavement, widows receive whatever rate had been in payment to their partner, except for the £61 supplement. A transition payment is also available for the bereaved parents of children under eighteen. and for orphans.

After six months following bereavement, widows whose circumstances are not described below will be paid £80 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. (ie A, B or C above - 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 (to a maximum of 3)	£30 each
if receiving any of Income Support, Family Credit, Council Tax Benefit or Housing Benefit and having dependent 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 PAYMENT

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	Convalescence breaks taken shortly after a hospital stay due to an HIV related illness.
Special Chairs/beds	Reclining chairs/beds as recommended by an Occupational Therapist.

Mobility

Motability	The Motability lease/hire scheme uses the registrant's Mobility Allowance to pay monthly hire costs over a three-year hire period, after which the car is exchanged. The Trust will only contribute to the Advance Payment for a car when there is no car in the NIL deposit range of Motability vehicles that is medically appropriate for the registrant's needs. A Motability Assessment or a letter from the Centre will be required to support the application.
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.
Driving Lessons	Course of driving lessons taken by the member or, where he/she is too young or 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 a local authority has agreed a Disabled Facilities Grant but the grant does not cover the full cost of the adaptations a top up grant of up to 25% of the cost of the work is available, or if the waiting time for the DFG is too great.
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. Not available for postgraduate level courses.
Special Costs	For specialist equipment or materials, or for 'Field Trips' but not for recreational school trips.
School Change Costs	School uniform, 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 9.00am and 5.00pm 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).

The application should include:

- **name and membership 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.**
- **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 doctors 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.**
- **Widows/partners, dependant children and other dependants will not normally need their application to be supported by a doctors report. However, a supporting letter from a social worker or other professional can be useful.**

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 members' requests. These meetings are normally held every three to four weeks, but emergency requests may call for a special meeting to be convened.

We will need to see receipts for items or services purchased that cost £500 or more.

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 or an Endowment Policy.

Limited mortgage protection might still be possible by taking out the endowment or 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)

The Trust may also be able to help with other costs of house moves.

Benefits

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 14-20 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.

Investments

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 through the Independent Financial Adviser, whose advice is completely impartial.

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 DSS 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 provide 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 £80 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 two other Trustees are Social Workers with HIV experience, so the Trustees have first-hand expert advice on medical matters concerning both 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 Bulletin.

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

The Trust's staff are not qualified to give detailed legal advice. 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. In addition, one of the current Trustees is a practising lawyer and might be able to assist in the provision or evaluation of advice in certain circumstances.

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

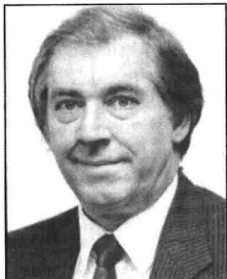
When someone dies, his/her affairs must be dealt with by a personal representative (otherwise known as executor or administrator) who will have to apply to prove the will or, if there is no will, apply for a grant of administration. In either case, contact the local Probate Registry Office (see your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

Trustees

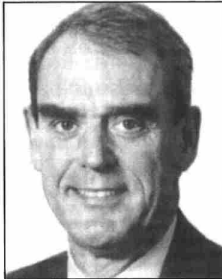
Nicholas Lawson



1998

Nicholas Lawson is currently Chief Executive and Managing Director of Lawson International Travel Services, a specialist travel company he set up 25 years ago geared to those who work in the travel industry. Nick previously managed hotels in Kenya, Cyprus and UK. He is a widower with three grown up sons. Nick lists his main interests as playing cricket and travel, watching any sports, listening to modern jazz and classical piano. Nick is a Trustee of the Katharine Dormandy Trust Haemappeal and was treasurer of the Haemophilia Society (1995-98). He has been a Trustee since March 1998.

Peter Stevens



1999

Peter Stevens is the father of a son and a grandfather. 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. He is also on the Council of Fairbridge. Trustee since July 1999.

Tony Yeaman



2000

Tony Yeaman is a solicitor and Partner in the national law firm of Beachcroft Wansbrough. His 22 year career in law has spanned general private practice, industry and the NHS. The last 13 years have been spent advising on all aspects of Health Service law and patient related issues. He is married to Jane who, as a Senior Nurse, worked for many years in the field of haemophilia. They live with their two children in Hampshire. Appointed Trustee in October 2000.

Pat Latimer



1999

Pat Latimer has been a social worker in the Haemophilia Comprehensive Care Centre at the Royal Victoria Infirmary, Newcastle upon Tyne, since 1989. Previously she worked as a children and families social worker in an area team in Gateshead, and had a special interest in adoption and fostering. She has an MA in Counselling and is a UKRC Registered Independent Counsellor. Appointed Trustee in July 1999.

Elizabeth Boyd



2000

Elizabeth Boyd 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. Appointed Trustee in September 2000.

Chris Hodgson



1992

Chris Hodgson has been involved with the Haemophilia Society (local and national) for many years. He was elected Chairman of the Haemophilia Society in July 1997. Chris completed a counselling course in 1996 and has been awarded a Certificate in Counselling from the University of Surrey. Chris was active in the motor trade for many years and was chairman of a group of garages. He is married with two sons and lives in Hampshire. Trustee since 1992.

Mark Winter



1996

Mark Winter is 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 currently involved in establishing a national haemophilia alliance which will bring together all of the organisations involved in the delivery of haemophilia care. Appointed Trustee March 1996.

Patricia Winterton CBE



1996

Pat Winterton worked at the Department of Health and, prior to her retirement in March 1992, was in charge of the branch concerned with hospital acute services. She is a Trustee of Marie Curie Cancer Care and several other charities and a Freeman of the City of London. Appointed Trustee March 1996.

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.
- Fran 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. Fran is in regular contact with Haemophilia Centres and The Society, and can contact Local Authorities and other bodies on your behalf.
- Jenny is our Benefits Advisor. She deals with queries about Social Security benefits and can help sort out problems with the DSS (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 Fran in preparing grant applications for Trustees and despatching payments to you all.

Jenny, Fran 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



September 1997

Fran



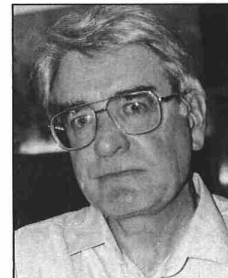
October 1997

Jenny



November 1995

Rodney



August 1999

Roz



September 2000

Welfare Benefits

There have been numerous changes to regulations since the handbook was first published. This year, rather than simply amending the information yet again, the whole section has been restructured. It covers 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 Adviser is generally at the Trust on Mondays, Tuesdays and Wednesdays. Otherwise, at the end of this section there is a list of advice agencies and publications.

The list of benefit rates has also 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 of 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 work, from those members either thinking of starting work or having to give up work.

STOPPING 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 (if 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 (see panel for changes). 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 on JSA.

To be paid IB, you must pass the "personal capacity assessment" or be deemed incapable and therefore exempt. See panel on page 16.

Severe Disablement Allowance

This has been the alternative to Incapacity Benefit for people who do not have enough National Insurance contributions. It is being abolished for new claims - see 'changes' panel on page 17.

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.

Working Families Tax Credit (WFTC)

You can claim WFTC if you work at least 16 hours per week, are on a low income, with savings of under £8,000, and have at least one dependant child. The amount of benefit depends on your income and the number and ages of your children. Childcare costs and the number of hours you work each week also affect the amount you receive. It is paid either by your employer or by the Inland Revenue.

Disabled Person's Tax Credit (DPTC)

You can claim this if you have a disability and are in a low-paid job. To qualify, your income must be low enough and you must have a disability which puts you at a disadvantage in getting a job. You must also be, or have been, getting a sickness or disability 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 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 are 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 of 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 April 1995 the ceiling has been £100,000. You should bear this 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 high 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)

Invalid Care Allowance (ICA)

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 £50 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 ICA 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 ICA 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 were over 58 on 13.4.95 and on Invalidity Benefit
- you are terminally ill and your death can 'reasonably be expected within six 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 tumour formation.'

The DSS has issued its doctors 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 bowel, 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 six 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.

Because of the extremely unpredictable nature of the illness experienced by someone with HIV, the DSS doctors who consider 'special rules' applications are forced to err on the side of generosity. We know that they look for evidence of a CD4 count of less than 200, any drugs associated with HIV, and symptoms. 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.

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 review. The rules which apply to reviews allow adjudication officers to backdate the awards for one month before the date of completion of DS1500s. 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.

WIDOW'S BENEFITS

Widow's benefits are based on your husband's NI contribution record. The present rules are set out below.

Widow's Payment

This is a tax-free lump sum payment of £1000 paid to widows under 60 at the time of widowhood. You must claim within 12 months of your husband's death.

Widowed Mother's Allowance (WMA)

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

Widow's Pension (WP)

This is a taxable weekly benefit for widows without children who are over 45 when widowed. If widow's WMA ends when they are 45 or over, they transfer onto Widow's Pension.

Widows who don't qualify for WMA or WP should consider applying for Income Support or Job Seeker's Allowance.

CHANGES

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

Incapacity Benefit: means-test (see p.14)

In April 2001, the amount of Incapacity Benefit will be reduced for anyone who also gets an occupational pension (IB will be reduced by 50p for every £1 of pension you receive over £85).

Severe Disablement Allowance (see p.14)

This will be abolished from April 2001. People who became incapable of work before age 20 will instead be able to claim IB even though they will not have paid National Insurance contributions. Full-time students aged between 20 and 24 will also be eligible if they are incapable of work and started their course before their 20th birthday.

Widows Payment (see above)

It is proposed to extend the benefit to include widowers and increase the payment to £2000. Childless widows and widowers over 45 will receive a bereavement payment for a maximum of 52 weeks. These changes will not take place until 2001 and existing widows will not be affected.

The Social Fund (SF)

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". Capital of over £500, insurance, other available assets and charitable payments are 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

Community Care Grants can be applied for by anyone who receives IS. Remember, you do not have to declare any payment you may be getting from the Trust. 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
- Draughtproofing
- 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 £1000. There have also been numerous smaller awards for items such as cookers and carpets that the Trust does not automatically help with.

Underclaiming And Other Problem Areas

Due to the complexity of the Income Support regulations there is widespread underclaiming. The main problem areas encountered by MFT 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 works out at £63.60 a week, although your parents will lose the Child Benefit paid 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 Office.

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.

Severe Disability Premium (SDP)

This premium can be allowed on top of the ordinary disability premium if you get 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 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.

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 three months to one 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 or Social Worker.
- 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.
- Backdate claims. Always seek maximum backing 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 forty 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.

Benefit Rates from April 2000

MEANS-TESTED BENEFITS

Income Support/ Non-contributory Job Seeker's Allowance

Personal allowances

single	
under age 18	£31.45/£41.35
aged 18-24	£41.35
aged 25 and over	£52.20
lone parent	
under age 18	£31.45/£41.35
aged 18 or over	£52.20
couple	
one or both under age 18	£61.35
at least one aged 18 or over	£81.95
dependant children	
to Sept after 16th birthday	£26.60
from Sept after 16th birthday to day before 19th birthday	£31.75

Premiums

family	£14.25
pensioner	
single	£26.25
couple	£40.00
enhanced pensioner	
single	£28.65
couple	£43.40
higher pensioner	
single	£33.85
couple	£49.10
disability	
single	£22.25
couple	£31.75
severe disability	
per qualifying person	£40.20
disabled child	£22.25
carer	£14.15

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	£31.45
aged 18-24	£41.35
aged 25 and over	£52.20

NON-MEANS-TESTED BENEFITS

Attendance Allowance

higher rate	£53.55
lower rate	£35.80

Child Benefit

only, elder or eldest child	£15.00
each subsequent child	£10.00

Disability Living Allowance

Care component

higher	£53.55
middle	£35.80
lower	£14.20

Mobility component

higher	£37.40
lower	£14.20

Earnings rule

Invalid care allowance	£50.00
Therapeutic earnings limit	£53.00

Invalid Care Allowance

increase for adult dependant	£24.15
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Incapacity Benefit

short-term (under pension age)

lower rate	£50.90
higher rate	£60.20

short-term (over pension age)

lower and higher rate	£60.20
short-term adult dependant	£31.50
long term	£67.50
long-term adult dependant	£40.40

increase of long-term for age

higher rate	£ 7.10
lower rate	£14.20

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

single person	£67.50
adult dependant	£40.40

Severe Disablement Allowance

adult dependant	£40.80
age related addition	
higher rate	£14.20
middle rate	£ 9.00
lower rate	£ 4.50
Statutory Sick Pay	
standard rate	£ 60.20

Improving the Trust's Service

In 1998 the Trust carried out an in-depth review of your needs, and submitted a report to the Department of Health at the beginning of 1999. The Review identified a number of possible new areas for grants to be made in, and confirmed that new treatments have had a considerable impact on the lives of many of you. Changes to the system of requests this year take account of this and have been made with the help of a Payments Review Group that included a number of those registered with the Trust.

COMMENT 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.

Appendix: Other sources of help, and general information

NATIONAL ADVICE AND SUPPORT ORGANISATIONS

AVERT (AIDS Education & Research Trust)

11-13 Denne Parade, Horsham RH12 1JD
(01403) 210202

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 Group (National)

PO Box 9, Abertillery NP3 1YD
(0345) 697231

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. Produces information sheets and a newsletter The Birchgrove.

Blackliners

Unit 46 Eurolink Business Centre, 49 Effra Road, London SW2 1BZ
020 7738 7468

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

Body & Soul

The Royal Homoeopathic Hospital, 60 Great Ormond Street, London WC1N 3HR
020 7833 4828

A self-help organisation supporting women, heterosexual men, their children and families living with or affected by HIV/AIDS.

British Liver Trust

Ransomes Europark, Ipswich IP3 9QG
0808 800 1000

CAB International

Wallingford, OX10 8DE
(01491) 832111

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
020 7837 7979

CPAG produce rights guides to welfare benefits and other benefits related publications.

Children with AIDS Charity (CWAC)

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

CONTINUUM

172 Foundling Court, Brunswick Centre, London WC1N 1QE
020 7713 7071

Continuum is an organisation for long-term survivors and for those who wish to remain healthy after HIV or AIDS diagnosis. It produces a monthly magazine, which covers alternative HIV/AIDS issues, drug effects, nutrition and lifestyle information, news, opinions and research challenging the AIDS orthodoxy.

CRUSAID Centre (The Information Exchange)

Chelsea and Westminster Hospital, 369 Fulham Road, London SW10 9TR
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
020 8332 7227

CRUSE offers to help to 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

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

020 7380 0600

Provides advice, support and assistance to people with haemophilia and their families.

NAM Publications

16A Clapham Common Southside, London SW4 7AB

020 7627 3200

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

0800 567123

24 hour national phoneline offering confidential advice, information and referrals on any aspect of HIV/AIDS to anyone.

MAINLINERS

38-40 Kennington Park Road, London SE11 9RS

020 7582 5434

Mainliners works with ex- and current injecting drug users and commercial sex workers affected and infected by HIV/AIDS and hepatitis.

Pos+Net HIV/AIDS BBS

The Positive Place, 52 Deptford Broadway, London SE8 4PH

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

020 7713 0222

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

020 7831 0330

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.

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Department of Social Security
The Adelphi 1-11 John Adam Street London WC2N 6HT

THE MACFARLANE TRUSTS

1. INTRODUCTION

This note explains how payments from the Macfarlane Trusts are treated for Social Security purposes. It also sets out the circumstances in which these payments may be passed on to certain other people without affecting their benefits.

2. WHICH BENEFITS?

The benefits which may be affected are:-

- Income Support
- Housing Benefit
- Community Charge Benefit
- Family Credit
- A Social Fund Payment
- Help with NHS costs

other Social Security benefits are not affected.

3. PAYMENTS FROM THE MACFARLANE TRUSTS TO BENEFICIARIES

If you are a beneficiary* of any of the Macfarlane Trusts, payments from the Trusts will not affect any benefit you receive from the Department of Social Security (DSS) or local authority. In addition, you do not have to tell the DSS or local authority that you have had a payment from any of the trusts.

If you decide to save or invest any payments from the Macfarlane Trusts you do not have to tell the DSS or local authority about these savings or investments or any income from them provided that you keep them separate from any other money you may have - for example, in a different bank or building society account.

(* A beneficiary is a person who is entitled to a payment from the Trusts, for example a haemophiliac. It does not include a person who receives a payment on behalf of a beneficiary or from a beneficiary.)

[4 to 8. These paragraphs refer to payments passed on to spouses, dependants, parents etc.]

9. REMEMBER - IF YOU HAVE OTHER INCOME AND SAVINGS

You, or anyone who is claiming for you, must let the DSS or local authority know about any other income or savings that you, your partner or children have.

10. FURTHER INFORMATION

If you are in doubt about any of the above or have any questions, for free and confidential information, please ring The Macfarlane Trust - 0171 233 0342.

GRO-C

MRS R J BUTLER
FOR SECRETARY OF STATE
FOR SOCIAL SECURITY

The Macfarlane Trust
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London SW1H 0QS
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