Your rights in the AIDS era. 9, Going into hospital / Immunity.

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immunity

Society for HIV Research and Education

9. Going into Hospital

This leaflet is in three parts. The first deals with some of your rights when you're in hospital. The second part gives guidance on what is likely to happen to your benefits while you're in hospital and the third section tells you how to claim some of the money you're entitled to when you leave hospital.

Rights While in Hospital

Many people want to know how much control they can have over their own lives while they're in hospital. The answer is that your agreement is needed for anything that affects you.

Obviously, you will be putting a lot of faith in the medical staff – but you are entitled to the last word about what they do.

You may be concerned about being tested for HIV antibodies. You are entitled to ask what tests will be carried out if you are asked for a blood sample and to have a say if you do not want to be tested for certain things.

On the other hand, testing may be necessary so that the best sort of treatment can be worked out, so you need to weigh up the options. You are entitled to have all the necessary information to enable you to do this.

For further information on testing for HIV see Your Rights in the AIDS Era, leaflet 1.

Whatever is done, you have a right to expect that your affairs will be kept private. Medical staff will get to know a lot about your medical condition and social and welfare workers will learn about your personal life. You are entitled to expect these confidences to be respected.

Even so, most of the rules about confidentiality are professional ones rather than enforceable by law. Those enforceable by faw say a health authority's employees shall pass on information about you only to other people concerned with your health care — or to prevent the spread of infection.

The staff at Immunity's Legal Centre can give advice on all the matters dealt with in this leaflet.

Going into hospital

With two exceptions, your benefit is likely to go down if you are in hospital for more than a few weeks.

The two that stay the same however long you stay there are Mobility Allowance and Statutory Sick Pay. SSP is payable for 28 weeks by your employer, so long as you remain employed. For more details on mobility allowance see Your Rights in the AIDS Era leaflet 8 or DSS leaflet NI 211.

In working out how long you have been in hospital for benefit purposes periods separated by less than 29 days are added together.

So, if you are in hospital for a succession of short stays you could find you benefit being cut.

After four weeks in hospital you will lose Attendance Allowance and any Severe Disability Premium dependent on it (but not Disability Premium). If someone who cares for you gets Invalid Care Allowance, that goes, too.

After six weeks there are reductions all round. If you are single without dependants, your Income Support will be reduced to £8.70.

Similarly, if you are receiving contributory benefits, like sickness or invalidity benefit, these will be reduced by £17.40.

The details of all the reductions, especially if you are living with a partner or have dependants, are too complicated for a short leaflet. You can get further details from DSS leaflet NI 9.

Housing benefit is paid even though you are no longer at home provided you intend to return and are not likely to be away for more than 52 weeks.

Payment will stop altogether after 52 weeks. Remember that in the meantime you will also still have to pay 20% of your rates bill out of your hospital pocket money.

Hospital Fares

If you have to travel to hospital and are getting income support or family credit you should be able to get your fares paid by the hospital.

You will have to produce evidence by way of your payment book or some official document. If someone has to take you to hospital, they can get their fares paid, too.

If you are not on Income Support or family credit but have a low income you can get help from the DSS. You can get the claim forms from the hospital. Form AG5 covers money you have already spent and form AG1 is to get a certificate so that you can claim future fares from the hospital.

You are normally paid the cost of second class public transport. There may be exceptions to this if you are physically incapable of travelling by public transport or there is none available. If you choose to travel by car you can get the cost of petrol up to the normal second class fare.

If you are visiting someone in hospital and are getting

Income Support you can apply to the DSS for a grant to cover travel. This is discretionary and is more likely to be given for visits to close members of your family. Grants are also payable for travel to a funeral but in this case they are restricted to family members.

Even if you don't qualify for any of the above, it's worth asking at the hospital if you are finding the cost of travel difficult. The hospital may have money available or know where you can get it. For further details see DSS leaflet H11 'Your hospital fares'.

Leaving Hospital.

When you leave hospital your benefits should go back up to the full rate from, and including, the day of your discharge.

Keep the DSS up to date about when you're going to go into hospital and when you're coming out. If you get paid too much because you don't keep the DSS informed you are likely to have to repay it.

You are entitled to benefit for any day you spend out of hospital. If you are allowed home for just part of the day — in preparation for returning home permanently, for instance — you will not be treated as being in hospital for that day, even though you go back to the hospital to sleep. So you can claim benefit for that day.

You may be able to get a Community Care grant, which is payable out of the Social Fund. Those grants are to help people on Income Support re-establish themselves in the community or to remain in the community. If you are physically disabled or chronically sick you are one of a priority group.

Community Care grants can cover such items as moving to more suitable accommodation or near to people who can care for you, connection or re-connection charges – but not telephones – bedding and, exceptionally, certain furniture and furnishings, a washing machine if it is essential, and clothing.

Any savings you have over £500 are set against the cost of the items. The minimum amount which may be awarded is £30, other than for travelling expenses where the grant can be less.

The grant's advantage is that you don't have to repay it. You might also get a Social Fund payment to cover rent in advance provided that would help to re-settle you or keep you in the community but it would be a loan and you'd have to repay it out of your weekly benefits.

If you apply for a payment from the Social Fund and you're turned down, you can't appeal against the decision. You can ask only for a Social Fund officer or inspector to review the decision.

LONDON AND NATIONAL GROUPS AND SERVICES

Afro Caribbean Helpline Service: Black advisers offering specialised advice and support, Pridays 6pm — 10pm, on the National AIDS Helpline (0800—667 123). Calls free

AIDS and Housing Project: Write:16-18 Strutton Ground, London SW1P 2HP AIDS Healthline: Information from the Colle-

ge of Health. Daily, 2pm — 10pm Asian AIDS Helpline: Advice given in Bengali, Gujarsti, Hindi and English, Wednesdays 6pm — 10pm, on 0800 — 282 445. Calls free Cantonese AIDS Helpline: Advice given in Cantonese, Tuesdays 6pm — 10pm, on 0800 —

282 445. Calls free

Body Positive: write PO Box 493 London W14 OTF. Mutual help and support group. Drop-in centre (from December, 1988) at 51b Philbeach Gardens, London SW5. Helpline: (7pm-10pm) 01-373 9124

Body Positive Support Group: For newly diagnosed people with HIV infection and others with the infection who are anxious, plus the lovers, close friends and relatives of both groups. Meets Sundays at 12.15pm (for 12.30pm) on the second floor at the London Leebian and Gay Centre, 69 Cowcross Street, London BC1

Care and Resources for People Affected by AIDS/HIV (CARA): write 40 Racton Road, London SWS. Phone 01—381 9656. Christian group offering support to Christians and non-Christians affected by HIV infection and by AIDS

Dentists who treat people with HIV infection: NHS Special Needs Dental Clinic, Alderney Street, London SW1. (Mondays, 3pm – 5pm, Tuesdays, Wednesdays 9am – 12pm) Phone: 01—630 8436 Or: advice on who to see from Mrs Satchell at City and Hackney Health Authority. Phone: 01—253 3020

Drug Users and Rx-Users with HIV infection/AIDS/ARC: run by Terrence Higgins Trust. Meets Pridays 7pm — 9pm at Trust's offices (62—54 Grays Inn Road, WC1) Info: David Bickerton on 01—831 0330

Ealing AIDS Response: Local group. Write: PO Box 16, Isleworth, Middlesex, TW7 6AG. Phone: 01—993 8872

Bast London HIV Social Group: Meets Mondays 8.30pm upstairs at the London Apprentice, 33 Old Street, London EC1. Info: Nigel Harvey on 01 — 377 7458

Prontliners: Mutual help and support group for people who have AIDS. Write: c/o Terrence Higgins Trust, BM AIDS, London WC1N 3XX. Phone 01—831 0330

Haringey Health Authority Helpline: Counselling and advice on the phone on 01—801 1490/01808—1061, extension 212 (10sm—6pm)

Haemophilia Society: Information, advice and support for everyone who has haemophilia — and special representation of and support for people with haemophilia infected with HIV by using Factor 8. Write: 123 Westminster Bridge Road, London SE1. Phone: 01—928 2020 Immunity: HIV research and health education charity. With full-time specialist legal centre for anyone with a legal problem connected with HIV infection, AIDS or an AIDS-related complex. Advice and court representation on offer. Also welfare rights advice. Open 10am—5.30pm. Phone to fix an appointment. Charity and legal centre at 280A Kilburn Lane, London W10 4BA. Phone: 01—968 8909

Italian Drug Users and Ex-Users Group: run by Terrence Higgins Trust. Meets Wednesdays 6pm — 7.30pm at Basement, SCODA, 1-4 Hatton Place, London BC1 8TD. Info-David Bickerton on 01-831 0330 or Dr Massimo Riccio on 01-352 8161

The Landmark: Open July 1969. Day centre for people who have HIV infection and people who have AIDS. Will offer advice, recreational facilities, meals. Plus info for other people. 47 Tulse Hill, London SW2. Phone 01—671.
2811/2

Lesbian Employment Rights: Non-AIDS specialist. Good on rights at work. Address: as LAGER Phone-01 — 587 1636 (Mon-Thur 7pm — 10pm)

Lesbian & Gay Employment Rights (LAGER): Specialist in rights at work. Mainly men. Write: Room 203 Southbank House,

Black Prince Road, London SE1 78J.

Phone:01—587 1643. (Mon-Pri, noon—5pm)

London Lesbian and Gay Switchboard: The
original helpline. Not an AIDS specialist—
but helpful. Write BM Switchboard, London
WC1N 3XX. Phone: 01—637 7324 (24hrs)

London Lesbian Line: Information, support.

London Lesbian Line: Information, support and advice for women. Phone 01—251 6911, Mondays and Fridays 2pm—10pm, Tuesdays-Thursdays 7pm—10pm

London Lighthouse: Hospice and drop-in centre. Offers counselling, health advice, support at home, breaks for carers and terminal care. 111 Lancaster Road, London W11 1QU. Phone 01—782 1200

Mainliners: Group for ex-drug users – and drug users who get their supplies on prescription – who have HIV infection or AIDS or a related condition. Write: PO Box 125, London SW2 8BP. Helpline-01 – 738 7333. Mon-Pr, 10mm – form

National AIDS Helplines: Phone — free of charge for free leaflets (0800—555 777) or confidential advice (0800—567 123). 24 hours a day

North London Social and Support Group: Info: Joe on 01 - 482 4107

Nurses Support Group: Runs helpline for healthcare workers who need advice and help on HIV problems, Mondays and Wednesdays 7pm — 10pm, on 01 — 708 5606

Positively Women: Group of women who have HIV infection or have AIDS. Meets in central London. Info; 01—837.9706 (Mondays-Pridays, 10am—5pm)

Project for Advice, Counselling and Education (PACE): One-to-one counselling and training in counselling. Meetings and write c/o London Lesbian and Gay Centre, 69 Coucross Street, London EC1. Phone: 01–251– 2689

South London Support and Social Group: Info: Rick, 01-678 3919

Standing Conference on Drug Abuse (SCO-DA): Information officer keeps up-to-date list of needle exchange schemes. 1—4 Hatton Place, London BC1. Phone: 01—430 2341/3 Terrence Higgins Trust: Information and counselling about HIV infection and AIDS. Plus support groups and trained volunteers to help people with HIV infection and people with AIDS. Write: BM AIDS, London WC1N 3XX. Phone: 01—831 0330 (admin only) 01—242 1010 (helpline, daily, 3pm—10pm)

Women's Reproductive Rights Information Centre: Not an AIDS specialist — helpful. Advice on all health issues affecting women, including HIV infection and AIDS, 52-54 Peatherstone Street, London BC1. Phone: 01-351 6332

Women's Support Group: Run by Terrence Higgins Trust. Info: 01-831 0330

What's AIDS?

AIDS is short for the Acquired Immune Deficiency Syndrome. If you have AIDS your body's defence system against all sort of infections is weakened so much you catch diseases which people whose immune systems aren't affected can just shrug off. And, when you catch them, the diseases turn out to be much more serious than they are in people with healthy immune systems. Nobody knows for certain, but it look as if everyone who has AIDS dies of one of the diseases they catch, such as a fairly rare form of pneumonia. You can't catch AIDS. It develops in you for some reason. HIV probably causes that to happen.

What's HIV?

HIV is short for the Human Immunodeficiency Virus. It was first discovered in 1983. Since then it has been called LAV and HTLVIII. But since 1986 the proper name for it has been HIV. It may cause AIDS to develop in you. You can catch HIV infection by allowing your body fluids — blood, semen or vaginal fluids — to become mixed with the body fluids of some who's already infected. HIV isn't like most viruses because, when you're infected it lives inside blood cells which are part of your body's defence system.

What's Immunity?

Immunity is a charity started in 1985 to research into HIV. Its aim is to find some way of helping people who have HIV infection stay well longer. It also runs fitness classes and produces education leaflets and relaxation tapes. With funds from the London Boroughs Grants Scheme, Immunity runs a legal centre in London to give advice and assistance to people who have HIV infection and people who have AIDS. Phone first before visiting to fix a time to call. The address and phone number are at the bottom of this page.

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