KF

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Living well into old age

Applying principles of good practice to services for people with dementia

King Edward's Hospital Fund for London is an independent charity founded in 1897 and incorporated by Act of Parliament. It seeks to encourage good practice and innovation in health care through research, experiment, education and direct grants.

The King's Fund Centre has a particular role in promoting advances in policy and practice in relation to problems of health and related social care. It offers a forum for informed debate, provides an information service and organises a range of activities designed to support local strategies for service development.

LIVING WELL INTO OLD AGE

Applying principles of good practice to services for people with dementia

King's Fund Centre

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Foreword

The Centre's fundamental objective of fostering improvements in services implies a keen interest in the current state of these services and a commitment to the careful monitoring of change. It also raises important questions about what constitutes 'improvement' and about the underlying principles and values on which any system of evaluation is based.

Much current monitoring machinery is inadequate. Resource constraints often mean re-assessing existing programmes and planning for the future on the basis of inadequate information and poor feedback systems. The search for better measures of cost effectiveness, work on accountability procedures and performance reviews, local and central use of 'performance indicators' all reflect the importance of service assessment in the current climate.

Members of the Long Term and Community Care Team began to look at these issues in relation to elderly people, and particularly to elderly people who experience dementia. Mindful of the influence of the 'an ordinary life' project on services to people with mental handicap it was felt that many of the lessons learned there could be used in parallel work for this other often neglected devalued group in our society.

Consultations began with concerned professionals in the field and early in 1984 a working party was formed. This project paper is the major result of their work.

The members of the working group came from a wide variety of backgrounds and could be said to reflect a multi-disciplinary approach to meeting the needs of people with dementia. However, they were not identified because they represented different professions or interest groups. They began to work together because they shared similar values and commitments to developing principles of good practice. They also recognised that these values should be presented in a context which made them readily available to all those who work in health and welfare services for people with dementia. Consequently, the document has been kept short and is organised so that it can be used for positive action. It is not academic but it is meant to be challenging. Above all else, it is intended to motivate without being prescriptive.

The working group has met regularly over a period of two and a half years with the support and resources of the King's Fund Centre providing an essential enabling facility. Ideas were tested with practitioners working in the field and with larger groups at conferences and workshops. Thus, the final document is only one part of a learning process which we hope will continue and result in a wide variety of outcomes in different parts of the country.

Introduction

Recently both the public and professionals have developed a greater interest in the needs of older people with psychiatric disorders. The large increase in the 'old old' (over 75) age group now occurring will probably be accompanied by an increase in disorders such as dementia, which become more common with increasing age. Influential publications, like the Health Advisory Service's *Rising Tide,* have highlighted the size and urgency of this challenging situation.

This paper aims to set out principles of good practice for services for these people. It focusses on dementia which represents the toughest challenge to any service for older people. However, similar principles can readily be applied to other severe psychiatric conditions.

Many service developments are currently occurring or being planned. The closure of some of the large Victorian psychiatric hospitals adds further pressure for new models of care-provision to be developed. Experience around the country shows that a number of barriers hamper good practice and hinder the development of high quality comprehensive services.

> Fundamental values and objectives for services have rarely been well-defined.
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> Development has centred on individual components – an assessment unit, a dementia team, a nursing home. Not enough attention has been paid to how individual people with dementia and their families experience the service as a whole.
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> Funding, staffing and management have been split between institutional settings (hospitals, residential homes, day-centres) and support services operating in the community (home helps, district nurses, primary care teams).
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> The planning and monitoring of services has too often taken place within parts of the system, rather than involving the whole. Often, there have been too few opportunities for those working at all levels in the system to make a contribution to planning and monitoring. In particular, frontline staff have been given little training, incentive or opportunity to participate in planning and evaluating services.
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> Evaluation of different service models has been hampered by the lack of a framework for comparing community based models with those emphasising care in institutional settings.
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> When evaluation is attempted, data that happens to be routinely collected is often used as a measure of effectiveness, rather than measures directly related to the goals of the service.
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> The need for expansion and innovation has at times meant that sufficient support has not been given to sustain existing good work.
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> Elderly people and their families and friends have had little or no say in the development or operation of services. At worst they are treated almost as scapegoats for the failures of the service: 'he can't attend this day-centre, she's too confused'; 'she'll need long term hospital care, the family won't have her back'.

This paper attempts to show a way forward that could overcome a number of these barriers.

It is intended to be used by all those who are involved in operating, planning or monitoring services for people with dementia. It begins by stating some key principles which we believe should underlie the provision and development of services. They involve basic values and attitudes. Not everyone will agree with them; they are presented to help everyone using the paper to clarify their own basic values and beliefs. We are convinced that making an explicit statement of principles underlying a service is essential to overcome the barriers listed above.

The paper also attempts very briefly to set out the *experience* of dementia from the perspective of the individual person and his or her family. This is intended to be of particular use to those not involved in frontline work with people with dementia. Frontline workers may however find it refreshing to think through the experience of dementia from these perspectives in relation to people with whom they have been involved.

The major part of the paper attempts to apply the key principles in practical terms; first for frontline staff and secondly for the managers of services.

Prompt questions are given to assist readers in thinking through the implications for their own situation.

A discussion of the applicability of the concept of citizen advocacy is included as an appendix to the paper. Many readers may be unfamiliar with this concept, which is important to our discussion of the rights of people with dementia.

The paper deliberately does not include examples of 'good practice'. Most of those known to us involve components of a service, rather than the system as a whole. There is also no mention of other factors that we view as secondary to our discussion of values and principles. These include: financial implications, resource management, and clinical effectiveness of medical and paramedical therapies. We recognise that systems may place their paid workers under various sorts of pressures and strains, some of which may be intolerable. Changing systems may potentially endanger career structures, employment rights of staff and so on. Safeguarding these rights must be the concern of the employees' organisations. Our concern here is with the rights of people with dementia.

Ensuring a good quality of life for people with dementia must be the concern of many different people: members of health and local authorities, senior managers and planners, 'frontline staff' (nursing staff, social workers, GPs, psychogeriatricians, geriatricians, occupational therapists, community psychiatric nurses, clinical psychologists and so on), voluntary agencies, pressure groups, service users and their representatives, members of local community organisations. Action is needed at all levels based on the experiences and achievements of service users – people with dementia and their families. A clear service philosophy can be a catalyst in bringing together the various people involved. From this starting point, action can be taken to enrich the day-to-day experience of each person with dementia, to modify professional practices as necessary and to create management and policy frameworks that allow these things to happen.

Some suggestions for using this document

While it may be useful for individuals to read this paper and think through the issues it raises on their own, positive action is much more likely to come from groups of interested people using the paper as a basis for discussion.

A group should include people who work in different parts of the service system and representatives of service users and frontline staff. There may already be groups that could profitably work through the paper – health care planning teams, for example, and new, informal, groups could be established.

Who could start such a group? Potentially anyone with an interest in improving services. For example, a community psychiatric nurse could invite a home help organiser, an officer in charge of a residential home, a social worker from a hospital psychogeriatric unit and a member of the local Alzheimer's Disease Society to meet. A health authority unit general manager could meet with an assistant director of social services, the director of the local Age Concern organisation, a consultant psychogeriatrician, a senior nurse planner and a representative of the local Association of Carers. One Age Concern branch already organises small meetings for those concerned with mental health of older people: GPs, social workers, a consultant geriatrician, a clinical psychologist, community nurses, home help organisers, and Age Concern workers meet together to discuss matters of mutual concern. It is possible to bring together people from different service components in this way – if somebody takes the initiative.

In choosing who to invite, consider who has most control over their own working patterns (and so can be involved in change most readily), who is committed to change, who is flexible in their ideas, prepared to collaborate, and who has positive attitudes. In other words, choose people who are going to be the most enthusiastic, cooperative and encouraging to work with in bringing about positive action.

Choose members of the group to ensure that it can consider both people with dementia living in ordinary community settings and those in residential settings in order to make links between them. Accept that no one group can make changes in every part of the system. Be clear about what you can change directly in the daily work of the group members and what can only be influenced by bringing pressure to bear on other parts of the system. Two ways in which frontline staff can influence those with management responsibility are to encourage service users (for example, carers' groups) to make their views known to the service managers, and for frontline staff to keep managers informed of those aspects of care plans for individual people with dementia that cannot be implemented for lack of appropriate resources.

The group should begin by clarifying their own basic principles in the light of the five which are basic to this document. Values ultimately are chosen rather than proven and it is not our intention to impose any one set of standards on elderly people, or on anyone else. Local groups may want to take our model as a starting point for discussion, and then to go on to generate alternatives.

The group can then continue to work through the paper, attempting to understand the experience of dementia in a personal manner. Using the prompt questions attached to each key principle will generate further questions and reveal relevant local issues, leading inevitably to ideas for positive action by individuals and by the group. Recognise and encourage practices that are working well already; and agree an agenda for action on specific tasks to bring about change where problems or failures have been identified. Over to you!

Key principles

This paper is about *practical* change in services but we believe that improvements can only be achieved by continually reviewing the principles held by people with a stake in changing services.

The principles of our existing services are very muddled. They are a mixture of government statements, the traditions of the past and day-to-day solutions to problems drawn up by staff. Much of the policy is unwritten. What is certain is that all policies involve some basic beliefs and values about the nature of mental disability and about the place of elderly people in society.

PRINCIPLE 1

People with dementia have the same human value as anyone else irrespective of their degree of disability or dependence.

People who do not work and people who have serious disabilities risk being undervalued in our society. Women, too, are often undervalued. Since many people with dementia fall into all three categories, they are at risk on all three counts. Expectations about quality of life for people with dementia must not be allowed to fall below the standards of other members of the community. Services should be concerned not just with meeting minimum standards but with positively demonstrating the value and importance of older people and people with dementia.

PRINCIPLE 2

People with dementia have the same varied human needs as anyone else.

This means not only basic needs for food, warmth, shelter and protection from physical hurt, but also for affection, companionship and opportunities to take part in worthwhile activities. They are entitled to share in the whole range of life's experiences as other citizens do, alongside other citizens in the mainstream of society. Only when they live as others do can people with dementia be accepted as having equal value. Only by living as others do will they have access to the same range of human contacts and resources. What we are aiming for here is not simply living *in* the community, in the sense of living outside a residential home or hospital or being cared for *by* the community without access to proper help from professionals and services; as we see it, real 'community care' implies being cared for *as a member of the community.* To achieve that objective for people with severe dementia and to help them to enjoy some of the benefits of community life will require a high level of long term support, professional skill, imagination and resources.

PRINCIPLE 3

People with dementia have the same rights as other citizens.

People with dementia are often denied their rights and the opportunities and resources to which they also have a right. In many cases, they are unable to assert their just demands on their own behalf. Where people with dementia do not themselves have the ability to claim their rights, it is the duty of those who serve them to find alternative means to claim on their behalf and to preserve their rights jealously. When formal steps are taken to change the legal status of an individual the safeguards and access to representation should be the highest standard expected by other citizens.

PRINCIPLE 4

Every person with dementia is an individual.

People with dementia, like anyone else, have the right to behave as individuals, within the limits of the law, and to be seen as individuals with their own preferences, abilities and needs.

One part of individuality is being helped in ways that are personally tailored to you. A second part is making sure that your individual history and past life are not lost and forgotten by those around you. Individuality means having continuity between your past, your present and your future.

PRINCIPLE 5

People with dementia have the right to forms of support which don't exploit family and friends.

It is the informal support of families, friends and neighbours which provides the major proportion of help for people with dementia. These carers have the right to expect a normal quality of life, without being exposed to stress and exhaustion. Those providing services have a duty to ensure that they actively recognise and support the work carried out by carers.

There are situations in which the needs and wishes of the elderly person conflict with those of the carers. Services should be concerned that both parties' rights are safeguarded.

The experience of dementia

People who may be elderly and who suffer from dementia remain first and foremost *people.* They have the same value, the same rights and the same broad, complex and varied human needs as other members of society.

The main consequence of dementia on these people is to reduce their ability to fulfil their human needs and to present themselves as valuable individuals without assistance from others. Giving this assistance is the prime task and is over and above the assessment of 'special needs'. We are concerned with providing support which does not diminish their humanity.

To understand the 'experience of dementia', it needs to be seen from the elderly person's point of view – how it disrupts and complicates the process of living a full life. It also needs to be seen from the carer's point of view – how to help the elderly person to live a full life without totally sacrificing the quality of the carer's life.

For the elderly person

Dementia is as varied as the individual people who develop it. The person's sex, character and personal relationships will determine how it develops.

One of the characteristics of dementia is that although the person may recognise problems when helped to see them, problems are rarely voluntarily expressed.

> Miss Phyllis Welford, a retired headmistress, aged 81, had been seen going out from home across a busy main road late in the evening. When stopped she had said she was going shopping. She had then been reminded of the time and had said 'How stupid of me! I thought it was ten in the morning' before she returned home. The next day she recalled nothing of the incident but said with a worried expression 'I do get a bit forgetful sometimes'.

The following features occur in the developing picture of dementia but a particular person will not manifest all of them to the same degree, or indeed many of them at all.

The basic changes of intellect, personality and behaviour are all undue changes not normally experienced.

Memory The fadeout time of current memory becomes faster, so that it is difficult to hold material in the mind. Concentration is therefore affected and becomes poor. Inappropriate memories of long ago may appear as current events.

Orientation Ability to recall 'where and when it is' increasingly dominates existence. The clues as to who other people are become increasingly difficult to recall.

Grasp Greater difficulty is experienced in teasing out what is going on and what is being said. This is particularly so if events move too fast, with little repetition to aid memory, or if a whole series of concepts are rapidly introduced.

Communication On top of the stresses of poor memory, poor orientation and poor grasps, there is a restricted power of communication, so that even if something is available in the memory it is not expressed.

Personality/emotions Because of the stresses caused by faulty mental mechanisms failing to deal with a normal environment, personality and emotional changes occur. There may be unusual 'defensiveness', 'irritability', 'withdrawal' or 'aggressiveness'.

Behaviour As mental mechanisms fail, so do coping strategies. There may be no decision making, and self-neglect follows. Decisions are made which are interpreted by others as 'wandering', 'aggression', and 'noisiness'. They may result in 'incontinence' and 'stripping off of clothes'. Such decisions are, however, made in good faith but are affected by faulty recall, orientation and grasp.

Monitoring of self Difficulty in steering self through 24 hours occurs because of inability to pay attention to normal memory cues. Eventually, day is turned into night. Life is lived from minute to minute.

Other common features complicate the process:

Reaction The stress of the failing mental mechanisms may cause normal reactions such as anxiety or depression. Sometimes the reaction may become severe enough to cause serious agitation or even misinterpretations, delusions and hallucinations.

Confusional states Physical illness frequently occurs during the course of dementia and gives rise to greater temporary mental disturbance. Drugs and social and environmental changes may have similar effects.

Neurological Some people with dementia may experience paralysis or abnormal body movements.

From the elderly person's point of view, therefore, this is a very stressful condition.

> Mrs Winifred Littlejohn, a widow aged 82, had lived with her sister – a tall, thin, single lady – for many years. She herself was short in stature but the more dominant character. She developed dementia. The first that was known of it was when she woke at 2 am, decided that the clock was wrong and ordered her sister out of bed to go shopping with her.
>
> She and her sister were picked up by the police in the city centre at 3 am. She was frightened and aghast at what had happened and could not understand exactly what had taken place. All her sister said was that she had been ordered to go shopping and there she was.

For the carer

The insidious onset of dementia is often inappropriately attributed by professionals and carers to 'old age' or to 'age itself', under the mistaken idea that age alone may give rise to such gross mental changes.

A negative response from a general practitioner or other professional may delay early supportive care. Her condition may be described in terms of 'her age', and treatment not arranged because 'nothing can be done'.

> Mrs Sarah Lunn's daughter was very tearful and tense when she was interviewed by the consultant for the first time. 'I thought it was old age and her doctor said it was her age', she explained; 'that was until a month ago, then she started swearing and hitting out at me'. 'What did the doctor say then?', asked the consultant. 'He said I should see you', she answered. 'The final straw was when I found her trying to go to bed in the dustbin...'
>
> The daughter broke down in tears. 'I've looked after her for five years, and I can't do any more. I'm not taking her home again'. She looked at her mother in bewilderment and at the consultant in defiance.

From the carer's point of view the major changes are an involvement in a baffling situation with a person who may be dearly loved, and a degree of care that becomes overwhelming and eventually obliterates normal life and social contacts.

Bereavement The carer gradually finds that the person has changed unbelievably, to such a degree that she is 'no longer my mother'. The carer has feelings of perplexity and the need to understand; she feels estrangement yet wishes to continue to care; has feelings of frustration, despair, even of rejection; yet feels guilty for feeling as she does.

24 hour care As the elderly person's abilities decline they need to be supported – the carer supports. As the elderly person neglects normal functions – the carer steps in. As the elderly person decides to do all the things which the carer thinks he/she should not do – the carer tries to intervene.

The carer gets mentally and physically exhausted.

Isolation As the elderly person loses touch with the rest of society and leads a life that is out of step with it, so does the carer in pursuit of caring. Friends no longer come in; the carer no longer goes out. There is no time for anything but caring.

> Mrs Martha Watt's daughter last took her mother out to their friends, Mr and Mrs Jones, two years ago. Her mother had behaved fairly normally for a while. However, just as the daughter was about to relax and had got engrossed in conversation, her mother left the dining table where they were eating lunch. She went out through the French window, went into a garden shed, pulled down her knickers and crouched down to pass urine.
>
> The daughter had felt so ashamed for both of them. She had left red faced, holding back floods of tears. Her mother was amazed at all the fuss. The daughter later recalled that her mother when young had had an outside toilet. She realised that she was acting now as if she was still going to it. However the daughter had no wish to go through similar experiences so they had not been out since then.

The general picture set out above emphasises the possible – all too common – destructive impact of dementia on the experiences and quality of life of the people involved. However it *is not a description of the inevitable,* but an agenda for action on the part of professional agencies. We do not have the means to prevent or cure dementia but there are a vast range of interventions – monitoring systems, orientation therapy, substitution personal care, counselling, medication and many others – which will modify the way in which the process of dementia is experienced by the people involved.

We believe that over and above the primary disabilities arising from dementia, there are major handicaps brought about by the ways in which the professional services operate. In a strategy for change one key element is to identify and alter these practices.

Principles into practice

In the next two sections we have set out our ideas about how the fundamental principles can be used to examine existing and proposed services.

Pages 14 to 23 take our five principles and spell out a few basic standards any individual might expect of a high quality service. Alongside these we have suggested some broad targets and sample questions which could form a basis for discussion among professional staff, friends, relatives and informal supporters, service managers, independent agencies and others who feel they have a stake in maintaining high standards of support and treatment.

The questions are based directly on the life and experiences of individual elderly people so that they can be applied to people living in a variety of places – the individual's home, a day centre, a hospital ward, a luxury hotel, a nursing home, a flat with intensive domiciliary staff support and so on.

In each case the process followed is one that can be repeated and improved on locally.

What does this mean for the individual?

Beginning with the principle, produce a list of a few basic everyday things which would show the principle in practice for the individual. How would the person *experience* this principle in action?

Implications for frontline staff and services

For each experience, consider what services would need to do (or stop doing) to make it happen.

Prompt questions

From these experiences and implications, produce a set of questions for each principle that will tell you something about how services are operating at the moment.

Our questions are a starting point. We hope that local groups using this paper will go back to the basic principles to generate more specific questions relevant to their local situation.

Implications for managers and planners

We hope that senior managers and planners will familiarise themselves with the material on pages 14 to 23, and use it. Managers have a responsibility to create the overall policy and resource framework within which frontline staff can work towards these standards. On pages 24 and 25 we have set twenty additional questions which managers and planners may find helpful in reviewing their performance in some of the strategic tasks of service development. These questions are also derived from the five principles and, once again, there is scope for more specific questions to be generated locally.

PRINCIPLE 1

People with dementia have the same human value as anyone else irrespective of their degree of disability or dependence. Quality of life depends on being seen by others as a person of worth and status, entitled to respect and dignity. Effective services make sure that they operate in ways which actively promote a positive image for the elderly people using the services and eliminate practices which in any way add to stereotypes or prejudices.

What does this mean for the individual?	*Implications for frontline staff and services*	*Prompt questions*
a. I do not want to be identified and labelled as some diagnostic category – a 'dement'– or referred to in derogatory terms.	a. The concepts, words and images used to refer to elderly people with dementia will be respectful and positive.	a. What words, abbreviations and jargon are used to refer to people with dementia in records, policy documents and professional discussion? What impressions are given by the signs, posters and logos which surround the person?
b. The place I live in must offer personal privacy when I need it. Sometimes I may wish to be alone while at other times I may like some company. I need a place where I can welcome people or turn them away.	b. The individual's environment will include a private bedroom, if they have not chosen to share with a spouse or friend. There will be a private area which each person has for their own use and which only friends or invited guests can normally enter. Professional skill and resources needed to actively sustain a sense of personal space for people with very severe memory and orientation difficulties will be seen as a priority.	b. What steps have been taken to ensure privacy and personal territory for sleeping, washing, eating, meeting friends and family – particularly for people with severe disabilities who require substantial assistance?
c. The place I live in and the activities I take part in must be appropriate to my status as a respected adult.	c. The individual's environment will be attractive, comfortable and normal in appearance. Everyday personal possessions and household goods will be apparent.	c. Does the outside and inside of the person's home look like an ordinary home? Do all the decorations and possessions seem appropriate to an adult rather than a child?

	Industrial equipment, large numbers of children's games, administrative equipment or notices will not be on display.	
d. I don't want my appearance or the things I do to suggest that I am inferior.	d. Each individual will have attractive personal clothing appropriate to their age and in line with their tastes and the standards of their friends and peers. They will have access to skilled help, if they need it, in performing everyday activities.	d. Would the individual's appearance make them stand out as inferior among other people in society? Is adequate skilled help available to enable the individual to perform everyday activities with dignity?
e. I want to be offered the kind of service that is available to any respected person – first class, skilled, prompt and relevant.	e. Age and disability will not in themselves be accepted as disqualifications for access to facilities and services used by other people. Professionals and informal helpers will be skillful in gaining access to these services. Services will aim for exemplary standards – the best we know how to do. . . .or better. Imaginative and thorough ways of monitoring the service will be maintained.	e. How easy is it for the person to get access to specialist professionals – a lawyer, an accountant, an optician, a tailor, a surgeon and so on? How do the levels of qualifications and experience of available staff compare with other staff working with younger or less disabled people? In what ways do staff and others monitor the quality of the services provided? What training is provided to staff and others on ways of monitoring the service?
f. I want to have contact with people who recognise that I have something to offer and who haven't written me off.	f. Staff and other helpers will be given information and training aimed at promoting a positive respectful view of people with dementia. Active attempts will be made to identify individuals in the wider community with positive attitudes and values, and efforts will be made to engage these people in the care systems as staff and in other roles.	f. Is staff training based on clear positive values and principles? Do recruitment and selection procedures stress the employment of people who hold these values rather than appointing on the basis of technical skills or qualifications alone?

PRINCIPLE 2

People with dementia have the same varied human needs as anyone else. Quality of life depends on fulfilment of a wide range of needs using the same means as other valued members of society. Effective services address a full range of needs in a coordinated way making use of ordinary resources and facilities to the fullest extent possible.

What does this mean for the individual?	*Implications for frontline staff and services*	*Prompt questions*
a. I do not want to be isolated from the mainstream of community life.	a. Professional help will be delivered wherever possible in ordinary community settings – ordinary houses, shops, clubs, GP's surgeries – rather than in special facilities used only by people with dementia. Where a more supportive environment is needed an over-emphasis on solutions based on special buildings must be avoided. Buildings may be necessary but they must evolve out of and respond to need rather than dictate what kind of service is offered. Generic services will be given assistance and advice in responding to the needs of elderly people with disabilities.	a. How much of the professional help available is provided in ordinary places – a house, social club, GP's surgery – compared to the help given in a specialised building – day centre, ward and so on – which is used only by people with dementia? In what ways do staff help the elderly person to use normal community services – banks, public transport, housing services, social clubs, shops?
b. I want to have *all* of my human needs recognised not just a roof over my head and physical care.	b. Assessment procedures will address a wide range of aspects of the person's life. High quality medical assessment and treatment for any physical health problems will be provided. Assessment activities will be carried out as far as possible in the person's everyday environment rather than a specialist unit.	b. How do the service providers find out about the needs of each elderly person? A recognition of the importance of each person's past life; a real home; giving and receiving affection and friendship; learning new skills; expression of sexuality; having adequate personal finances; physical health. Which needs have the greatest priority?

c. I want my daily schedule and programme of activities to have the right balance between familiar routine and variety.	c. There will be a clear system for 'case management' across different professions and services to ensure that the overall package of support is understood and coordinated. This process will ensure that activities take place in appropriate settings and that the schedule offers some of the variety of everyday life. There will be effective systems for coordination within and between agencies contributing to this programme of care.	c. How are the various activities of professional staff and other forms of help coordinated so that the individual has a consistent package of support? Is there a named person responsible for the overall package of care for each elderly person. How is information about gaps, overlaps and problems collected and used? Does daily life for people with dementia include being in different places and doing different things at different times?
d. The place I live in and the other facilities I use must be easily accessible to me and to other family and friends who may want to visit me or help me live my life.	d. The services will be as local as possible. Public and other transport arrangements will be effectively coordinated. Any physical or cultural barriers which might reduce access to services will be removed. By these and any other means contacts with family, neighbours and friends will be safeguarded.	d. How far are services organised and provided locally. How long does it take to reach them? Does the location of the building, its physical features or past associations in any way discourage elderly people or other visitors? What specific steps are taken to make or maintain contact with family and friends?

PRINCIPLE 3

People with dementia have the same rights as other citizens. Quality of life requires opportunities for autonomy, choice and access to independent safeguards against infringement of legal and civil rights. Effective services recognise the right of service users to participate fully in the planning and control of the help offered to them. They recognise that there may be occasions when the needs and wishes of people who use the service may not be compatible with those of the staff and service managers.

What does this mean for the individual?	*Implications for frontline staff and services*	*Prompt questions*
a. I want to be involved in important decisions about my life.	a. The individual will be given as much information as possible about the options open to them. Staff will be given training on the skills and methods which may be appropriate for this. The views and opinions of the person will be adequately recorded and conveyed to other appropriate individuals and agencies.	a. What arrangements exist for giving individuals full information about the options open to them; finding out about their own opinions and wishes? How are the services tackling the difficulties of doing this adequately for people with dementia?
b. I want to be able to exercise choice and control over my day-to-day environment and how I spend my time.	b. There will be safeguards to ensure that the individual is able to retain control over, and make choices about, some aspects of everyday life. Aids, adaptations and equipment will increase the individual's control over the environment.	b. How strong are the statutory and legal rights of individuals in the places where they are living? How do they currently control their money and decisions about spending it; their immediate surroundings, such as room temperature, lighting, control of electrical and domestic equipment; the choice of being alone or with other people; where, when, what and how much they eat; what they wear?

c. If I need help in getting my voice heard and my interests represented I want it to be easily available to me. If I become incapable of making my own decisions I would like somebody who has taken the time to get to know me to act on my behalf.	c. A system of independent advocacy for the person with dementia will be developed.	c. What arrangements exist for individuals to have access to independent advice by someone not connected with immediate carers or staff? What opportunities are there for them to have an independent advocate who knows them and who will act as their representative when they are unable to act for themselves?
d. I want to be safeguarded against physical and verbal abuse and I want my possessions to be protected against theft and damage.	d. Each individual, their personal property and private territory will have the same forms forms of protection as any other member of society including access to lockable private areas and storage space, as well as opportunity to make use of legal and formal complaints procedures.	d. What arrangements are there to safeguard the living space of the person against unwanted intruders? What arrangements are available to store and lock away valued items without removing them from the person's everyday environment? What access does the person have to legal and other complaints machinery?

PRINCIPLE 4

Every person with dementia is an individual. Quality of life depends on maintaining personal continuity between the past, present and future, and on being recognised as a unique individual with a distinctive pattern of capabilities and needs. Effective services adapt themselves to match the previous life and circumstances of the person. They design and maintain individually tailored packages of care and have the flexibility to adapt the amount and form of help provided to match day-to-day and longer term changes in the individual.

What does this mean for the individual?	*Implications for frontline staff and services*	*Prompt questions*
a. I want to have contact with and get help from people who have really taken the time to get to know me.	a. Assessment and planning of support will not be done purely on routine information and diagnostic or dependency checklists. People who already know the individual will be fully involved, and professional staff will be organised so that they are able to get to know a small number of individuals with whom they work over a long period of time.	a. How are families, friends and others involved in creating an overall picture of the person? What arrangements have been made to ensure that staff have both the skills and the time to establish a close relationship?
b. I want to live with my personal possessions around me because they say something about who I am and what I have experienced and done in my life. I want to live and spend my time in places where I can maintain activities and routines which have been important to me over the years and where I am not forced to change.	b. Decisions to move people away from familiar homes and daytime activities will only be taken after everything has been done to maintain them in their current surroundings. Relocation will be carried out gradually so that sudden change is minimised.	b. Are there some clear guidelines about the levels of home support which need to be tried before any relocation is considered? Are staff resources available for immediate deployment to avoid 'crisis admissions'?

c. I want to be seen as an individual, not always as one of a large group with similar characteristics.	c. The scale of provision will be as small and ordinary as possible.	c. Does the service ensure that people live and spend their time with others of their own choice, rather than a group who may have little of common interest? How far is care planning and advocacy organised on an individual rather than group basis?
d. I want the amount of help offered to me to vary for different activities and from day-to-day as my needs and capabilities change.	d. There will be a system for regular monitoring of needs, and a capacity to respond to changes in short-term or long-term needs.	d. What steps are taken to make sure that the level and type of help available depends on the needs of the person rather than on the working hours and practices of the professionals? Do people have to move from one place to another if they need more or less intensive help? Is there a named individual responsible for looking at the overall package of care for the person with dementia?
e. I want to be known and referred to by the name I choose.	e. The identity of the individual will be recognised and acknowledged by service providers.	e. How are individuals consulted about how they want to be addressed?
f. I do not want to be denied opportunities to change and develop, whatever my age or disabilities.	f. Consistency and continuity in the life style and support of individuals will always acknowledge the possibility of change and growth, irrespective of the age and disabilities of the person with dementia.	f. How are opportunities provided for people to maintain activities and develop new interests?

PRINCIPLE 5

People with dementia have the right to forms of support which don't exploit family and friends. Quality of life depends on relationships that are reciprocal and voluntary, and in which the rights and needs of everyone are respected. Effective services recognise and support the contribution of relatives and informal networks who provide the overwhelming amount of care available to people with dementia.

What does this mean for the individual and their carers?

a. If I have family, friends and other contacts who want to assist me and with whom I feel comfortable, I would like them to be able to continue to help me without experiencing stress.

Implications for frontline services and staff

a. Appropriately trained staff will be responsible for locating and contacting all the people who are supporting the person with dementia. All possible means to support, extend, enrich and, if necessary, create a group of carers will be tried before any decision is made to offer alternative institutional provision. The support available will be sufficient to ensure that where a carer, for whatever reason, withdraws support, the quality of life of the person with dementia will not be catastrophically reduced. The relatives' and other carers' feelings of guilt or failure will be kept to a minimum. The professional system will not exert pressure on them to continue caring beyond their abilities to cope and the carers will not be blackmailed by the offer of unacceptable alternatives to continuing to care.

Prompt questions

a. How are the existing networks of contacts and supports identified? In what ways do the professional services provide help to the family and carers – financial and material assistance, access to staff time and skills, and so on – as alternatives to offering direct professional help to the person with dementia?

b. We don't want to have to wait until a crisis point is reached before we receive help.	b. Services will maintain a good local information system on people with dementia and their carers who have been identified as potential users of the mental health services. Opportunities for early contact with carers and the provision of assistance with minor problems will be one of the activities of the service.	b. How many other people with dementia are there in the locality? How much staff time is allocated to working alongside carers on specific tasks, or taking over from them for a short period, compared with the time spent in long term 24 hour professional care?
c. We want to know what professional services and assistance are available to complement what we are willing and able to do.	c. A variety of channels and methods will be used to pass information to carers and to draw together their views and experience of current and proposed services.	c. How are carers told about the availability of professional services? What steps have been taken to find out whether carers know about local services and to consult them about their views on these services?
d. We want friends and family to have a strong voice in how, when and what professional services are provided for us.	d. A coherent care plan involving all agencies and supporters in contact with the person with dementia will be drawn up. The emphasis will be on the formal professional services changing and adapting to fit the informal network, rather than vice versa.	d. Do carers have opportunities to decide the timing, level and type of professional input? How are professional practices which carers see as unhelpful identified and changed? What local examples are there of professional practices and services created at the request of carers?
e. We want it to be recognised that there may be occasions when the wishes and interests of the person with dementia will be at odds with those of family and friends, and that both have to be protected.	e. Sources of advice and independent advocacy will be available for families and supporters which are separate from those serving the person with dementia. Carers will be offered opportunities to meet together for mutual support, discussion, education and counselling, and to agree joint action to improve the current support systems.	e. Is there a local source of advice, support and representation for carers which is independent of the professional services and of any advocacy service for people with dementia? How are carers offered the resources and support to meet and work together on common problems?

Implications for managers and planners

Twenty key questions

Principle 1 People with dementia have the same human value as anyone else irrespective of their degree of disability or dependence.

Recognising the status and worth of people with dementia.

1. Have the health and local authorities established a senior leadership group with clear responsibility for overseeing the development of the total local service for people with dementia?
2. Have all members of this leadership group been involved in agreeing the principles and values which will underlie the services? How has this set of principles been disseminated among authority members, professional staff and community organisations? How are they used in activities such as staff recruitment or training?
3. Have the authorities set up effective arrangements for quality assurance in the day-to-day running of services? How are services being monitored against the agreed principles and values?

Principle 2 People with dementia have the same varied human needs as anyone else.

Responding to a full range of needs within the mainstream of society.

4. Are people with dementia denied access (for whatever reason) to generic health and local authority services? How is this situation reviewed?
5. How do senior managers review the system of services for people with dementia as a whole? How are resources allocated across different areas of activity – assessment and case planning, treatment, long-term support, crisis services, and so on – and how is the overall balance of priorities decided?
6. Have the authorities set up a number of small planning teams which are sufficiently 'near the ground' to involve staff who know individual service users well, and to involve local people with knowledge of neighbourhood resources?
7. Have resources been allocated to set up and support local forums where a wide range of professionals and agencies can meet regularly to maintain contact and coordinate their activities?
8. Have financial, manpower and staff management systems been created to focus service planning in each of the smaller localities which make up the authority?
9. In allocating the budget, does the authority give a clear priority to employing staff who will work with people with dementia in a variety of ordinary settings – their own homes, GPs' surgeries, local recreational facilities, and so on – in preference to investing in special purpose-built facilities? How do the two sums compare at the moment and how are they reviewed?

Principle 3 People with dementia have the same rights as other citizens.

Promoting the rights of people who use the services.

10. What attempts have been made to find out the users' views about the service offered?
11. What guidance or training has been provided for staff to identify individual preferences and offer meaningful choices to people with very severe disabilities?
12. What arrangements have been made to provide access to independent representation and advocacy (for example through the CHC, a law centre, CABS or citizen advocacy project) particularly for people with dementia who are highly dependent? What channels are used to monitor and investigate complaints?

Principle 4 Every person with dementia is an individual.

Creating individual-centred services.

13. How do resources allocated to schemes serving people with dementia as individuals or in small groups (that is, less than six) compare with allocations to larger projects (that is, buildings and campuses for 20, 50 or more)?
14. How are the deficiencies and problems picked up by staff planning individual care programmes collated and made available to the leadership group?
15. How much extra training and professional and personal support have been provided for staff who are required to undertake a more flexible and individualised style of working?
16. Have all members of the senior leadership group spent at least eight hours of a day in the company of a person with a severe degree of dementia?

Principle 5 People with dementia have the right to forms of support which don't exploit family and friends.

Safeguarding the rights and quality of life of families and other carers.

17. What procedures are followed to make sure that carers are fully involved in assessments and in drawing up individual care plans for people with dementia?
18. Have independent studies of the views and experiences of carers been carried out within the authority and how has the information been used?
19. Has a comprehensive information and advice service been set up which can be used by carers? Has a system of support and representation been established for carers which is independent of the professional services and separate from advocacy arrangements for people with dementia?
20. Have places been made available for carers to participate in service planning activities at local and central level?

Appendix I Advocacy and people with dementia

Introduction

One underlying theme of this document is our concern that people with dementia should have a strong voice to influence the decisions that affect their lives. To achieve this, people need to be able to represent themselves or be given some form of independent representation. Recently, a new approach to this problem – advocacy – has emerged in this country, especially in services for people with mental handicaps. An account of these early developments, together with a paper on the American experience, is contained in a recent King's Fund publication.*

What follows is an attempt to clarify the concept of advocacy and to consider its implications for people with dementia. Particular attention is given to citizen advocacy, which is a form of special intervention with and on behalf of people who find it difficult to speak for themselves. We argue that the case for the introduction of citizen advocates into the long-term care services is both appropriate and necessary.

When people are deprived of the opportunity to represent themselves, other interests take over. This is inevitable when those who become highly dependent on others get 'locked' into closed forms of provision. Their needs, wants and rights become predefined and the variety and quality of choice and opportunity are seriously limited, if not eradicated altogether.

'Other advocacy'

People who cannot control or influence decisions which directly affect their lives come to rely on 'other advocacy' for the protection and representation of their interests.

Anyone who has known people who have lost the ability or desire to articulate and defend their own interests must be aware of their growing need for 'other advocacy'. As family and/or friends cease to be able to provide the necessary support, professional advocacy tends to take over.

Consequently, professional advocacy has come to be recognised as the most sufficient and effective form of representation for people who are highly dependent on others. In the case of people with dementia, it is usually left to nurses, psychiatrists, administrators, social workers and so on to interpret and defend the interests of '*their* clients'. Access to multi-disciplinary teams, which might be seen as an attempt to resolve potential differences between groups of professionals, is often denied to people with dementia and their lives become circumscribed by much narrower group interests (namely, in large institutions or private sector 'homes').

The 'conflict of interest' dilemma

The assumed sufficiency of professional advocacy – a plank upon which service provision can safely rest – presumes a coincidence of interests between the users and the providers of services. This was neatly summed up recently by a nurse who declared 'if we learned to do our work better, then no one need worry about the quality of life experienced by our clients'.

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* *Advocacy* R Sang and J O'Brien. King Edward's Hospital Fund for London, 1984.

This well-intentioned but arrogant assertion reflects the commonly held and widely promoted assumption that professionalism – backed by appropriate resources – can by itself create good practice in service delivery. Such expectations are both dangerous and misleading.

In reality, serious conflicts of interest exist between service users and service providers. They are inevitable and irreconcilable – the trick is to learn how to live with them.

Conflicts of interest occur when

- people share the same
  - space
  - time
  - resources
- decisions are made by others about
  - personal life
  - daily needs
  - social life
  - special needs

That is, when choices/opportunities/risk are defined by others. Moreover, conflicts of interest do not go away, in spite of a host of possible remedies, namely

goodwill
good intentions
planning
expertise
the 'right approach'
the 'right attitude'
training
professionalism

Elderly people with dementia share space, time and resources with others. They are subject to a multiplicity of decisions made by other people. Different people in different ways have a stake in *their* lives. The more intellectually impaired they become the less likely they are to have an influence on their own existence. *If people cannot/do not participate in the decisions which affect their lives, then conflicts of interest become a growing problem.* Day in, day out, service providers interpret other peoples' needs in ways which reflect other priorities and constraints. This is *not* a criticism of professionals and other carers: it is an observation on the reality of their working lives.

This reality is also concerned with power – especially power of decision. When an individual or a group hold power of decision over others, some form of countervailing influence is needed to redress the balance. If this does not happen, services become distorted. They reflect the interests of those with power. Large psychiatric hospitals are the obvious example; *but* the best run community facility in the most enlightened service organisation can experience similar distortion of interests.

If people with dementia are to exert an influence on *their* services *who* can help them to participate?

To people who work in 'EMI' establishments this question may seem to be irrelevant nonsense. Associating the idea of 'participation' with people who are reaching the end of their lives, and who appear to be incapable of rational thought, is hard to accept.

But experience in long-stay mental handicap institutions in the United States and Scandinavia, and now in the United Kingdom, has shown that even the most profoundly handicapped people can be involved in effective participation. The means of doing so is known as 'Citizen advocacy'.

Citizen advocacy

Citizen advocacy occurs when an ordinary citizen develops a relationship with another *person who risks social exclusion or other unfair treatment because of illness or handicap. As the relationship develops the advocate chooses ways to understand, respond to, and represent the other person's interests as if they were the advocate's own.* *

A citizen advocate is

an independent person who is free from conflict of interest (that is, not a relative or staff person);

a willing, committed member of the local community; (more than a friend; that is, someone who is prepared to pursue an individual's rights and entitlements in addition to providing companionship and support).

For example, citizen advocates have provided one-to-one friendship for some residents of long-stay hospitals in Surrey and Middlesex. In some cases they have obtained full welfare benefits (including substantial arrears) for the people they have befriended. In others, they have opened the door to much needed special treatment.

More important, on a day-to-day basis they have begun to ensure that those they have befriended are seen and responded to as individuals, not categories or labels. This enhancement of personal dignity and respect has had powerful and positive consequences for the residents involved. They are valued people who can and do influence decisions which affect their lives through the efforts of their advocate.

The Advocacy Alliance scheme, which was established in 1981 by five mental handicap charities, is run entirely in mental handicap hospitals. Their model assumes that citizen advocacy is based on a one-to-one friendship which entails a long-term commitment. However, this model is not prescriptive and would need to be adapted if applied to other settings and people with mental ill health. For example, the Sheffield Advocacy Project relates to people who live in a wide variety of community-based accommodation.†

Can 'citizen advocacy' help people who are old and experience dementia?

The short answer is *yes,* but the implications need to be worked through carefully. In particular, it is important to ensure that a new proposal is built on the key principles which underpin any citizen advocacy scheme and clarify its identity and purpose.

Dr Nan Carle, in her excellent Key Concepts series††, has elucidated the essential elements of such schemes:

No conflict of interest. In order to safeguard the advocate and promote loyalty to the person he or she represents, it is necessary for the advocate and the citizen advocacy scheme to be independent from the service provider or potential service provision agency. This is especially true for the funding, administration and location of the scheme.

Recognition of this independence was built in to Advocacy Alliance's agreements with the health authorities who ran the hospitals in which it worked. However the Alliance itself was made up of service providing organisations and the majority of funding came from the DHSS. Not an ideal situation by any means.

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* John O'Brien in *Advocacy* op. cit. page 27

† Sheffield Advocacy Project, 14-18 West Bar Green, Sheffield S1 2DA

†† Published by Campaign for Mentally Handicapped People, 12A Maddox Street, London W1

The debate about the *independence* of citizen advocacy is a heated one. Should there be compromise on the conflict of interest problem in order to achieve some sort of advocacy scheme? Should programmes be demonstrably independent from services or organisations which might inhibit or even prevent progressive action by advocates? On the other hand, can citizen advocacy in the United Kingdom survive without direct support from service agencies and their staff?

One-to-one relationships involving unpaid volunteers. A major feature of the lives of people who become dependent on services is that nearly everyone involved in their lives is either paid to be there, or is someone who shares the same label – 'old', 'EMI', 'senile', 'disabled', and so on. But advocacy is not a job; it is a relationship between one individual who is handicapped in some way and another from outside their daily service-centred experience.

Is this realistic where people who are old and experience dementia are concerned? Surely, there can be no incentive for volunteers in this context? But, without such relationships, it will not be possible to know what these people really want/need from life. Such 'realistic' questions deny the appropriateness and validity of independent representation for people with dementia.

Sustained relationships. Citizen advocacy envisages long-term relationships based on friendship and the fulfilment of individual rights and entitlements to services and a good quality of life.

Again, is this feasible? How can anyone represent, let alone befriend, someone who is incapable of meaningful communication? What would sustain the relationship? Who then is to provide continuity in the lives of people who often experience profound social exclusion? Surely it is at the time when people begin to lose the ability to speak for themselves that continuity and communication become most important if individual representation is to be achieved?

These are serious questions, and there are many others. When these issues are discussed with professionals involved in psychiatric services they have questioned the relevance of citizen advocacy for people with dementia. In particular, they have raised questions about the following.

Accountability: Can advocates be made answerable to any authority in view of the fact that they would be involved with extremely vulnerable people?

Treatment: Should advocates concern themselves with this aspect of an individual's life, especially medication?

Friendship: Is it really possible, on either side, for such expressive relationships to develop? How are they going to be initiated?

Relationships with staff: Won't these degenerate into an argument about who knows best, carried on over the patient's head?

Relationships with relatives: Aren't citizen advocates going to usurp the role of relatives, many of whom will have supported earlier decisions about what is good for the patient?

Conclusions

These are questions which have been confronted at one time or another by people involved in citizen advocacy schemes here and elsewhere. Indeed, they could be said to characterise these schemes.

They are a healthy sign that someone is pushing back at the day-to-day assumptions made by service organisations about their 'clients'. It could be asked in return:

> How can services be made accountable to people with dementia?
>
> Should not treatment be questioned as a matter of course?
>
> What happens when older people don't have friends?
>
> What happens when staff and/or relatives' decisions are not questioned?

In practice, the quality of service delivery and the quality of life rarely, if ever, reflects an *individual's* wants and needs. It may be that intervention by a citizen advocate cannot always be based on friendship with people with dementia. But, unless a way is found of seeing the world from where they sit, it is unlikely that acceptable services will be achieved. Acceptable, that is, in terms of the criteria developed in this document.

Citizen advocacy, with or without friendship, places an independent person in a situation where they can 'understand, respond to, and represent the other person's interests as if they were the advocate's own'. The question then is not 'can citizen advocacy help people with dementia?', but 'what will their lives be like *without* this form of intervention?'

Appendix II Further reading

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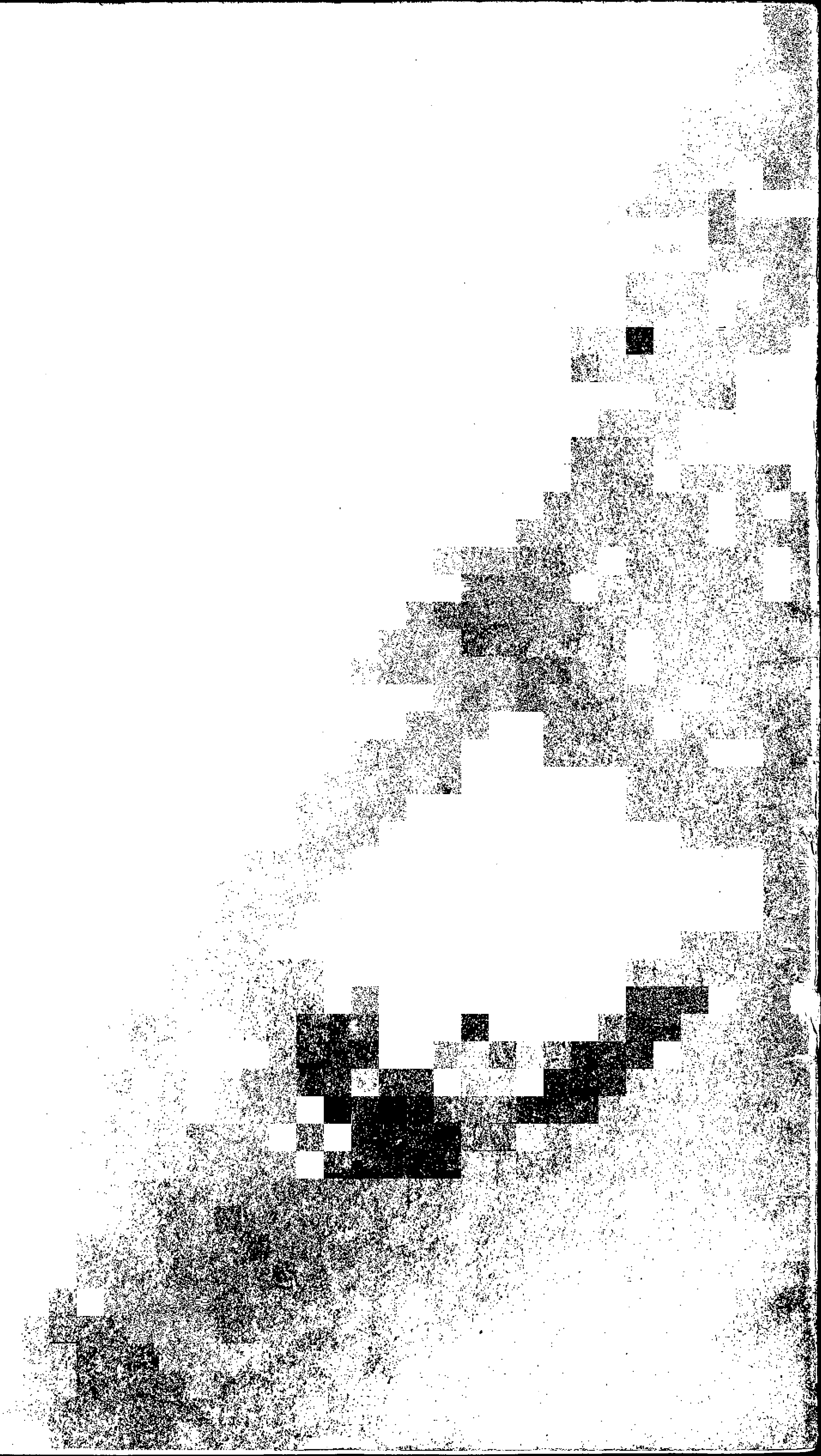

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