

Report by the Health Service
Ombudsman for England of an
investigation into a complaint
made by Ms B

Report by the Health Service Ombudsman for England of an investigation into a complaint made by Ms B

Presented to Parliament pursuant to Section 14(4)
of the Health Service Commissioners Act 1993

Ordered by
the House of Commons
to be printed on 15 July 2013

HC 558

London: The Stationery Office

£8.75

© Parliamentary and Health Service Ombudsman (2013).

The text of this document (this excludes, where present, the Royal Arms and all departmental and agency logos) may be reproduced free of charge in any format or medium providing that it is reproduced accurately and not in a misleading context

The material must be acknowledged as Parliamentary and Health Service Ombudsman copyright and the document title specified. Where third party material has been identified, permission from the respective copyright holder must be sought.

Any enquiries regarding this publication should be sent to us at phso.enquiries@ombudsman.org.uk.

You can download this publication from our website at www.ombudsman.org.uk.

ISBN: 9780102986433

Printed in the UK for The Stationery Office Limited

on behalf of the Controller of Her Majesty's Stationery Office

ID 2573529 07/13

Printed on paper containing 75% recycled fibre content minimum

Contents

Foreword	2
Summary	3
Introduction	4
The basis for our determination of the complaint	5
The investigation	10
Final remarks	22

Foreword

I am laying this report before Parliament to help others learn from the service failure and maladministration it describes.

This complaint is about a GP practice which did not give a young man with severe learning disabilities, behavioural problems and epilepsy, the medication he needed on the grounds of cost.

The report describes service failure, specifically that the practice failed to consider their obligations under disability discrimination law, and did not follow accepted medical guidelines. This resulted in distress for the complainant and her son.

In March 2009 my predecessor, Ann Abraham, and the Local Government Ombudsman, Jerry White, published *Six Lives: the provision of public services to people with learning disabilities*; six reports that illustrated some significant and distressing failures in service across both health and social care, leading to situations in which people with learning disabilities experienced prolonged suffering and inappropriate care. This report is a reminder that even four years on, we continue to see examples where the NHS is failing to meet its obligations to some of its most vulnerable service users.

Regular training of health staff on the *Mental Capacity Act*, as recommended by the recent Confidential Inquiry into Premature Deaths of People with Learning Disabilities, is one step which could help address this issue.

Dame Julie Mellor, DBE
Health Service Ombudsman

July 2013

Summary

Background to the complaint

Ms B's son, Mr H (who was 23 at the time of the events complained about), has severe learning disabilities and behavioural problems. He also has epilepsy. Mr H has historically been prescribed a series of medicines that he takes in liquid or dissolvable form because he becomes very distressed if he has to take tablets. One of those medicines is midazolam, which is used in emergencies if his epileptic seizures last beyond three minutes.

Ms B attended the Practice in April 2011 for a repeat prescription of midazolam. However, she said that she was advised that she would need to see Dr L, a GP at the Practice, to discuss her son's medication. Ms B attended an appointment with Dr L on 3 May and she said that he told her that the Practice would not prescribe midazolam for Mr H because it was too expensive.

Ms B said that Dr L also told her that he would no longer prescribe any of Mr H's other medicines in liquid form for cost reasons and that he would only prescribe tablets in future. Ms B said that when she questioned Dr L about this, he told her to find a GP '*who has bigger budgets*' and who would '*be happy to prescribe the medications*'. Ms B said that this decision not to prescribe her son suitable medication put him at risk, including death.

Ms B subsequently complained to the Practice about Dr L's decision. As a result of this, Dr L wrote to inform her that there had been a '*total breakdown*' in the doctor-patient relationship and advised her to find a new GP within 21 days or he would remove her and Mr H from his list of patients (the Practice's list). Ms B said that this caused her significant distress and inconvenience.

Introduction

1. This is the final report on the investigation into Ms B's complaint about the Practice. This report contains my findings, conclusions and recommendations with regard to Ms B's areas of concern.

The complaint

2. Ms B has asked us to investigate her complaints about:
 - the Practice's decision to refuse to prescribe her son suitable medication, which put him at potential risk, including death; and
 - the Practice's threat to remove her and her son from their list of patients when she made a complaint about this, which caused her significant distress and inconvenience.
3. Ms B would like the Practice and Dr L to acknowledge that they were wrong to refuse to prescribe her son suitable medication and to unfairly threaten her and her son with removal from the Practice's list, and she would like the Practice and Dr L to apologise for this.

Our decision

4. Having considered all the available evidence related to Ms B's complaint about the Practice including her recollections and views, and taking account of the clinical advice we have received, I have reached a decision.
5. I find that the care and treatment that the Practice provided for Mr H fell so far below the applicable standards that they constituted service failure. I find that Mr H and Ms B suffered injustices in consequence of the service failure that I have identified.
6. Furthermore, I find maladministration in the way the Practice made Ms B and Mr H withdraw from their patient list and that Ms B suffered an injustice in consequence of the maladministration that I have identified.
7. I therefore uphold Ms B's complaint about the Practice.

Our jurisdiction and role

8. By virtue of the *Health Service Commissioners Act 1993*, we are empowered to investigate complaints about the NHS in England. In the exercise of our wide discretion we may investigate complaints about NHS organisations such as trusts, family health service providers such as GPs, and independent persons (individuals or organisations) providing a service on behalf of the NHS.
9. When considering complaints about GPs, we may look at whether a complainant has suffered injustice or hardship in consequence of action taken by the GP in connection with the services the GP has undertaken with the NHS to provide. Service failure or maladministration may arise from action taken by the GP himself or herself, by someone employed by or acting on behalf of the GP, or by a person to whom the GP has delegated any functions.
10. If we find that service failure or maladministration has resulted in an injustice, we will uphold the complaint. If the resulting injustice is unremedied, in line with the Principles for Remedy, we may recommend redress to remedy any injustice we have found.

The basis for our determination of the complaint

11. In general terms, when determining complaints that injustice or hardship has been sustained in consequence of service failure and/or maladministration, we generally begin by comparing what actually happened with what should have happened.
12. So, in addition to establishing the facts that are relevant to the complaint, we also need to establish a clear understanding of the standards, both of general application and those specific to the circumstances of the case, which applied at the time the events complained about occurred, and which governed the exercise of the administrative and clinical functions of those organisations and individuals whose actions are the subject of the complaint. We call this establishing the overall standard.
13. The overall standard has two components: the general standard, which is derived from general principles of good administration and, where applicable, of public law; and the specific standards, which are derived from the legal, policy and administrative framework and the professional standards relevant to the events in question.
14. Having established the overall standard, we then assess the facts in accordance with the standard. Specifically, we assess whether or not an act or omission on the part of the organisation or individual complained about constitutes a departure from the applicable standard.
15. If so, we then assess whether, in all the circumstances, that act or omission falls so far short of the applicable standard as to constitute service failure or maladministration.
16. The overall standard I have applied to this investigation is set out below.

The general standards – the *Ombudsman's Principles*

17. The Ombudsman's Principles of Good Administration, Principles of Good Complaint Handling and Principles for Remedy¹ are broad statements of what we consider public organisations should do to deliver good administration and customer service, and how to respond when things go wrong. The same six key Principles apply to each of the three documents. These six Principles are:
 - Getting it right
 - Being customer focused
 - Being open and accountable
 - Acting fairly and proportionately
 - Putting things right, and
 - Seeking continuous improvement.
18. The Principle of Good Administration particularly relevant to this complaint is:
 - '*Getting it right*' – which includes that public organisations must act in accordance with the law and with regard for the rights of those concerned, and with recognised quality standards, established good practice or both, for example about clinical care. Public organisations must also take reasonable decisions, based on all relevant considerations.

¹ The *Ombudsman's Principles* is available at www.ombudsman.org.uk.

The specific standard

Disability rights

19. Public authorities (and some other organisations with public functions) and service providers are required to comply with the *Equality Act 2010*, which includes the duty to make reasonable adjustments. They should also have regard to the various statutory codes of practice that have been published to assist in the interpretation of the legislation.
20. Under the *Equality Act 2010*, public organisations have a general duty to eliminate discrimination and harassment, to promote equality of opportunity and positive attitudes, to encourage participation in public life, and to take steps to take account of disabled persons' disabilities, even where that involves treating disabled persons more favourably than other persons.
21. In 2010 *The Equality Act 2010 Statutory Code of Practice: Services, Public Functions and Associations* (the Code) came into force. The Code made it clear that a service provider's duty to make reasonable adjustments is owed to disabled people at large and that the duty is 'anticipatory':

'The duty to make reasonable adjustments requires service providers to take positive steps to ensure that disabled people can access services. This goes beyond simply avoiding discrimination. It requires service providers to anticipate the needs of potential disabled customers for reasonable adjustments.'
22. Between 1998 and 2001 the Department of Health published a number of documents relevant to people with disabilities, one of which was the White Paper, *Valuing*

People: a new strategy for learning disability for the 21st Century. The thrust of these documents was to support the Government's strategy and objectives for achieving improvements in the lives of people with learning disabilities, by helping the NHS meet its duties under the *Disability Discrimination Act 1995*. The intention was that '*All public services will treat people with learning disabilities as individuals, with respect for their dignity*'. One of the objectives was to '*enable people with learning disabilities to access health services designed around individual needs, with fast convenient care delivered to a consistently high standard, and with additional support where necessary*'.

23. It is not our role to adjudicate on matters of disability discrimination law or to determine whether the law has been breached; that is a matter for the courts. The Principles of Good Administration do, however, say that the Principle of '*Getting it right*' includes acting in accordance with the law and with regard for the rights of those concerned, and taking reasonable decisions based on all relevant considerations.
24. If it appears to us that someone's disability rights are engaged in relation to the events complained about, we will expect the public organisation, in accordance with the Principles of Good Administration, to have had regard to those rights in the way it has carried out its functions, and to have taken account of those rights as a relevant consideration in its decision-making.
25. If the public organisation is unable to demonstrate that it has done so, we will take that fact into account when considering whether there has been maladministration and/or service failure.

26. In cases where we identify maladministration and/or service failure, it does not necessarily follow that we will also find that injustice has been caused as a result.

The Mental Capacity Act 2005

27. The *Mental Capacity Act 2005* provides the legal framework for acting and making decisions on behalf of individuals who lack the mental capacity to make particular decisions for themselves. Section 1 of the *Mental Capacity Act* sets out a number of principles which apply for the purposes of the *Mental Capacity Act*, including that:

(2) A person must be assumed to have capacity unless it is established that he lacks capacity ...

(5) An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.

(6) Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.'

28. Section 4 of the *Mental Capacity Act* makes provision in connection with determining what is in the best interests of a person who lacks the capacity to make a particular decision. Section 4(7) requires the person making the determination of what is in a person's best interests to 'take into account, if it is practicable and appropriate to consult them, the views of ... anyone engaged in caring for the person or interested in his welfare'.

29. The statutory *Mental Capacity Act 2005 Code of Practice* published in April 2007 to provide guidance on how the *Mental*

Capacity Act works on a day-to-day basis (the *Code of Practice*) explains that:

'The Act's starting point is to confirm in legislation that it should be assumed that an adult (aged 16 or over) has full legal capacity to make decisions for themselves (the right to autonomy) unless it can be shown that they lack capacity to make a decision for themselves at the time the decision needs to be made. This is known as the presumption of capacity. The Act also states that people must be given all appropriate help and support to enable them to make their own decisions or to maximise their participation in any decision-making process.'

'The underlying philosophy of the Act is to ensure that any decision made, or action taken, on behalf of someone who lacks the capacity to make decisions or act for themselves is made in their best interests ...'

'An assessment of a person's capacity must be based on their ability to make a specific decision at the time it needs to be made, and not their ability to make decisions in general.'

30. Under the heading 'What are the statutory principles and how should they be applied?' the *Code of Practice* says that:

'Before somebody makes a decision or acts on behalf of a person who lacks capacity to make that decision or consent to the act, they must always question if they can do something else that would interfere less with [a] person's basic rights and freedoms. It includes considering whether there is a need to act or make a decision at all.'

31. Under the heading ‘What does the Act mean when it talks about “best interests”?’ the Code of Practice says that:

‘Under the Act, many different people may be required to make decisions or act on behalf of someone who lacks capacity to make decisions for themselves. The person making the decision is referred to throughout this chapter, and in other parts of the Code, as the “decision-maker”, and it is the decision-maker’s responsibility to work out what would be in the best interest of the person who lacks capacity ...

‘Where the decision involves the provision of medical treatment, the doctor or other member of healthcare staff responsible for carrying out the particular treatment or procedure is the decision-maker ...’

Legal standards

32. *The National Health Service (General Medical Services Contracts) Regulations 2004* (GMS Regulations) sets out the provisions that must be included in agreements concerning the circumstances in which GPs can remove patients from their lists.
33. Paragraphs 19 to 27 of Schedule 6 to the GMS Regulations set out the provision relating to the removal of patients from a GP’s list.
34. The GMS Regulations contract signed by Dr L, on behalf of the Practice, sets out his specific duties and powers as to the removal of patients from the Practice’s list. It is that contract which imposes a duty on the Practice to comply with the mandatory conditions which the GMS Regulations require to be included in the contract.

Paragraph 192 of the contract in this case says:

‘... where the [Practice] has reasonable grounds for wishing a patient to be removed from its list of patients which do not relate to the applicant’s race, gender, social class, age, religion, sexual orientation, appearance, disability or medical condition, the [Practice] shall ... notify the patient in writing of its specific reasons for requesting removal.’

35. Paragraph 194 of the contract says:

‘... the [Practice] may only request a removal under paragraph 192, if, within the period of 12 months prior to the date of its request to the PCT, it has warned the patient that he/she is at risk of removal and explained to him/ her the reasons for this.’

36. There are some exceptions to this requirement. For example, if the GP has reasonable grounds for believing that the issue of such a warning would be harmful to the physical or mental health of the patient or would put at risk the safety of the GP, practice staff or any other person present on the practice premises; or where, in the GP’s opinion, it would ‘*not otherwise be reasonable or practical*’ to give such a warning. The GP should record in writing the date of any warning given and the reasons for giving such a warning as explained to the patient, or the reason why no such warning was given.

Professional standards – the General Medical Council

37. The General Medical Council (the GMC – the organisation responsible for the professional regulation of doctors) published *Good Medical Practice* in 2006 and *Good Practice in Prescribing*

Medicines in 2008 (GMC guidance), which contain general guidance on how doctors should approach their work. GMC guidance represents standards that the GMC expects doctors to meet. It sets out the duties and responsibilities of doctors and describes the principles of good medical practice and standard of competence, care and conduct expected of doctors in all areas of their work.

because of the resource implications of the patient's care or treatment'.

38. GMC guidance says that when prescribing medicines doctors must ensure that the prescribing is appropriate and responsible and in the patient's best interests. It says that to do this doctors must:

'reach agreement with the patient on the use of any proposed medication, and the management of the condition by exchanging information and clarifying any concerns. The amount of information you should give each patient will vary according to factors such as the nature of the patient's condition, risks and side effects of the medicine, and the patient's wishes.'

39. It says that bearing these issues in mind, doctors should, when appropriate, *'establish the patient's priorities, preferences and concerns'* and *'discuss other treatment options with the patient'*.
40. GMC guidance says that doctors must also *'treat patients as individuals and respect their dignity'*.
41. It says that in rare circumstances, the trust between a doctor and a patient may break down and that doctors may find it necessary to end a professional relationship. However, it says that doctors *'should not end a professional relationship with a patient solely because of a complaint the patient has made about [the doctor] or [his/her] team, or*

The investigation

42. We telephoned Ms B on 3 July 2012 to discuss the nature of her concerns and how we would investigate the complaint. We confirmed our understanding of the complaint and the issues we would investigate in a letter to Ms B dated 6 July 2012.
43. During this investigation we have examined all the relevant documentation. This includes papers provided by Ms B, Mr H's GP records and the papers relating to the attempted resolution of the complaint at local level. We have taken account of the comments received from Ms B in her correspondence to us. We have also taken account of the comments received from all parties on the draft report.
44. We also obtained clinical advice from one of our clinical advisers, a registered GP (the Adviser). Our clinical advisers are specialists in their field, and in their roles as advisers to us they are independent of any NHS organisation.
45. In this report I have not referred to all the information examined in the course of the investigation, but I am satisfied that nothing significant to the complaint or my findings has been omitted.

Key facts

46. Mr H has epilepsy and has been diagnosed with a learning disability with challenging behaviour. He has also been diagnosed with unspecified mental retardation (his communication is at the level of a four or five year old) with significant behaviour impairment that requires attention or treatment. He is under the care of a consultant psychiatrist and a nurse specialist in epilepsy. Mr H also receives support from a community learning disabilities nurse (the Community Nurse) based in the community learning disability team of his local authority.
47. Mr H has been prescribed a series of medicines by both his psychiatry and neurology teams. The medicines include lamotrigine dispersible tablets, levetiracetam oral solution and carbamazepine oral solution to prevent and control epileptic seizures. They also include risperidone oral solution, which is prescribed to calm erratic behaviour, and lactulose solution for constipation. Mr H has also been prescribed midazolam solution which is used in the mouth if he experiences prolonged epileptic seizures of more than three minutes.
48. Mr H and Ms B had been registered with the Practice since 2007. Mr H's GP records note that he has learning disabilities and behavioural difficulties and that he should be prescribed liquid medication. Ms B said that in early 2011 she had to get a new prescription of midazolam for her son because his current supply was reaching its expiry date. However, she said that the Practice had refused to issue a new prescription. Ms B said that she contacted the Community Nurse, who faxed a request for a new prescription of midazolam to Dr L. Records show that this happened on 28 February. However, Dr L responded with a brief note (date unknown) explaining that '*we will not do this prescription*'. He said that he would prescribe rectal diazepam instead.
49. Dr L spoke to the Community Nurse on 23 March. He noted that he wanted to find out why Mr H needed to have midazolam. Dr L recorded that he was not willing to prescribe the drug at a cost of £80 when rectal diazepam was just as good. He wrote to the Community Nurse on 5 April confirming his decision not to prescribe

midazolam. Dr L said that *'the cost of midazolam oral liquid is just over £90'* and *'it is no more effective than diazepam rectal tubes [which cost] just under £2'*. He said that the Practice had to justify every prescription that was issued *'in the present economic climate'*. Dr L once again requested to know the clinical reason why Mr H required midazolam rather than diazepam.

50. Ms B visited the Practice in late April to collect Mr H's prescription for midazolam. She said that she was told by the Practice's receptionist to make an appointment with Dr L so that he could discuss her son's midazolam and all his other medications. The appointment took place on 3 May. The note of the appointment shows that Dr L told Ms B that he was no longer willing to prescribe her son's medications in liquid form and that he suggested that she changed her GP. Dr L recorded that Ms B told him that her son will not take tablets. However, he noted his view that there was no clinical reason why Mr H could not swallow tablets as he was able to eat normally. Dr L noted that he had told Ms B that he had to consider costs and this was the decision of the Practice as a whole.
51. Records show that Dr L repeated this view in a conversation with the Hounslow Primary Care Trust's (the PCT's) prescribing adviser the next day (following a complaint by Ms B to their Patient Advice Liaison Service). He then had a further two conversations with the PCT's prescribing adviser about Mr H's medication on 16 and 17 May. Dr L issued a new prescription for Mr H immediately after his last conversation with the PCT. The prescription shows that he had changed Mr H's risperidone and levetiracetam oral medication to tablet form and that he had prescribed rectal diazepam instead of midazolam liquid.

52. Ms B said that she and her son registered at a new GP practice on 8 July, and that the PCT's prescribing adviser met the new GP prior to Mr H's first consultation to advise on his medication (which the new GP subsequently prescribed in liquid form). She said that her son was supplied with midazolam by his new GP on 28 November. The PCT later told us that their records indicate that the Practice did not initiate any formal action to remove Ms B and Mr H from the Practice's list.

The progress of the complaint

53. Ms B complained to the Practice following her appointment with Dr L on 3 May 2011 and outlined the events that led to her complaint. She said that her son had always taken his medication in liquid form from a very young age because he cannot swallow tablets. Ms B said that in the past she had tried giving him paracetamol in tablet form but it had caused him to vomit. She said that she had never experienced any problems in getting her son's prescribed medications until her appointment with Dr L.
54. Ms B said that her son attends college and a respite centre as well as being a member of a community club and football team. She said that all the organisations that her son goes to have people who are trained to administer his midazolam in the event that he has a prolonged seizure. Ms B said that her son's seizures were unpredictable and that they could occur anywhere at any time. She said that they could happen at college, or in a shopping centre, and asked how it would look if someone had to administer rectal diazepam to her son in public.

55. Ms B further explained that Dr L had told her that he would no longer prescribe any of her son's medications in liquid form because of their high cost and that he would only prescribe tablets. She said that he also told her that she needed to find her son '*a GP who has bigger budgets, would take [Mr H] on, and be happy to prescribe the medications*'. Ms B confirmed that she did not want to change her GP because she was happy with the service that both she and her son received from the other GPs at the Practice and that they had never had any problems previously.
56. Dr L responded to Ms B's complaint (copied to the PCT's prescribing adviser) on 17 May. He said that all the GPs at the Practice had discussed the issues raised by Ms B and that he had also spoken to the PCT's prescribing adviser about her concerns. He reiterated that as Mr H had no swallowing difficulties, he was not willing to prescribe liquid medication for the reasons he discussed with her at the appointment on 3 May.
57. Ms B wrote to Dr L again on 26 May. She said that she was '*very annoyed and disgusted*' to learn that Dr L was not willing to prescribe liquid medication for her son. Ms B said that it was unfair of Dr L to advise her to find another GP, and that her appointment with him was more about his budget than her son's health. She confirmed that her son did not have physical problems swallowing. However, she said that he did have issues with taking any form of tablets. Ms B said that this was due to his severe learning disability and that he '*displays behaviour that of a child although he is 23 years of age*'.
58. Ms B said that she had previously spoken to the practice manager and had agreed that she would try giving her son tablets instead of his liquid medication. However, she said that after careful consideration she did not think that this was a good idea. Ms B reiterated that she had recently given her son a paracetamol tablet. She said that it had caused him to vomit and display very bad behaviour. Ms B said that she could not see herself dealing with this on a daily basis given that she had to go to work as well as sorting out her son's medications and coping with his behaviour.
59. Ms B also asked Dr L to explain how her son's carers would administer rectal diazepam when he is out in public. She said that it would be inappropriate. Ms B said that she would not be administering rectal diazepam to her son in public or in private and that it would cause him to display very bad behaviour to both her and his carers when he found out. Ms B said that she would be returning all her son's diazepam and asked Dr L to reconsider his position and prescribe the medications in liquid form. She confirmed that she would not be finding another GP practice for her son. Ms B said that as her son's parent and appointee she was exercising his choice to remain at the Practice.
60. Dr L responded to Ms B on 31 May. He said that '*following national and local PCT guidelines*' he would not be changing his decision about Mr H's medication. Dr L said that from the tone of Ms B's letter, the Practice felt that there had been:
- 'a total breakdown in [the] doctor/ patient relationship and it would be in the [sic] best interest if [Mr H] and you change your general medical practitioner within the next twenty one days, otherwise we as a practice will have no option but to remove you from our list of patients.'*

61. Ms B submitted a further complaint to the Practice and the PCT on 21 June as a result of Dr L's response. The PCT, after a considerable delay, responded to Ms B on 21 February 2012 (the Practice did not provide a further response).
62. The PCT said that after receiving Ms B's complaint about the Practice, they had asked a nurse consultant for learning disability to meet Ms B and Mr H to assess Mr H's medication needs and provide a report. They said that the report agreed with Ms B's view of the inappropriateness of administering rectal medication in public in relation to her son's privacy and dignity. The PCT said that while it is important for GPs to understand the cost of the drugs that they are prescribing, and to prescribe appropriate alternatives if they are more cost effective, they were firmly of the view that in the case of Mr H *'the alternatives [that Dr L prescribed] were not appropriate'*. They confirmed that they did not have a policy with respect to this issue.
63. Regarding Dr L's threat to remove Ms B and Mr H from the Practice's list, the PCT said that they did not consider that a patient making a complaint regarding treatment was *'sufficient reason to remove them from the list'*. They added that it was *'contrary to the [NHS] complaints regulations'*. The PCT concluded that it was better for the care of Ms B and her son that they were now at a GP practice that met the needs of Mr H.
64. Ms B submitted a further complaint to the Practice and the PCT on 21 June as a result of Dr L's response. The PCT, after a considerable delay, responded to Ms B on 21 February 2012 (the Practice did not provide a further response).
65. Dr L said that he reached his decision because Mr H had no difficulty swallowing solids and that he could eat normal meals. He said that neither Mr H nor Ms B had ever reported to doctors that Mr H had swallowing difficulties.
66. Dr L said that he had discussed his decision not to prescribe liquid medication with Ms B on more than one occasion and the Practice were not going to change the decision. He clarified that he had not declined to prescribe the medication requested by Ms B on behalf of her son, but rather he had prescribed alternative cost-effective medication in line with local and national guidelines.
67. Dr L said that at no point was Ms B threatened with removal from the Practice's list. However, he said that he did advise her that it was in her and her son's best interests to register with another GP practice. Dr L said that this was because there had been a total breakdown in the doctor-patient relationship and Ms B was clearly not happy with the service that she was receiving from the Practice. He confirmed that Ms B and Mr H were not removed from the Practice's patient list.

Meeting with Dr L

68. We met Dr L on 15 November 2012. He reiterated that he had been following PCT guidelines in not prescribing Mr H's medications in liquid form. Dr L confirmed that these guidelines were not contained in a formal written document. He said that they were instead *'informal guidance'* that had been part of various conversations that he had had with the PCT and the

PCT's prescribing adviser. Dr L said that the PCT's prescribing adviser had confirmed that his decision to not prescribe Mr H's medication in liquid form was correct and supported by the PCT.²

69. Dr L said that as far as he was concerned, he had done everything correctly in relation to prescribing Mr H suitable medication, and he had followed national guidelines. He said that his decision had not only been made on cost grounds but had also been a clinical decision. Dr L said that there was no physical reason why Mr H could not swallow tablets, and it was his view that the medication that he was willing to prescribe for him was suitable for his needs.
70. Dr L confirmed that in reaching his decision not to prescribe Mr H liquid medication, he had not taken into consideration his legal rights as a person with disabilities.

Clinical advice

71. The Adviser said that all GP practices are being asked to review their prescribing costs and to reduce the amount of unnecessarily expensive drugs that they prescribe. She said that liquid forms of drugs are often more expensive and it is reasonable to consider whether cheaper alternatives to these can be prescribed.
72. However, the Adviser said that the individual needs of the patient should always be considered when making these decisions. She said that doctors are therefore required to act in the patient's best interests and this requires them to make a balanced judgment on whether the patient will come to any harm if a cheaper

drug is substituted. The Adviser said that doctors should always discuss the reasons for changing medications with the patient and take their opinions into account.

73. The Adviser said that when Dr L decided to review Mr H's medication, he should have immediately noticed from the GP records that it had been documented that Mr H had learning disabilities. She said that this should have led Dr L to consider Mr H's learning disabilities in any decision that he made about his medication.
74. The Adviser said that because Mr H had been diagnosed with learning disabilities and behavioural problems, Dr L should have arranged to consult with him and his mother so that an assessment of his ability to make an informed decision about his medication could be made under the terms of the *Mental Capacity Act*. She said that Dr L should have also liaised with Mr H's wider multidisciplinary team because they would have had expertise that could have helped him decide whether Mr H had the capacity to make informed decisions about his own care.
75. The Adviser said that if Mr H was assessed as being unable to make his own informed decision about his own care and treatment under the *Mental Capacity Act*, then a 'best interests' decision should have been made. She said that in making a decision on what would be in Mr H's best interests, Dr L would have been required under the *Mental Capacity Act* to consult other people such as Ms B and the wider multidisciplinary team, especially in relation to the requirement that would least restrict Mr H's basic rights and freedoms.

² Dr L said that there were no records of his conversations with the PCT's prescribing adviser about Mr H's medications and that several emails that had been sent about the matter had been deleted. He confirmed that the prescribing adviser no longer worked at the PCT.

76. The Adviser said that Dr L should then have explained the costs of her son's medications to Ms B and explored with her if there were any suitable ways of using alternative medications. She said that the discussion should have taken into account the advice of the other health professionals involved in Mr H's care because they would have an understanding and knowledge about him. The Adviser said that Ms B's concern about the impact on her son's dignity in relation to being administered a rectal drug in public should have also been taken into account by Dr L. She said that being able to eat food does not necessarily mean that a patient can swallow tablets and that Dr L could also have discussed with Mr H's pharmacist if alternative medications could be used in other ways, for example, crushed in meals.
77. The Adviser said it is very important for patients who have epilepsy that medications are changed by specialists. She said that this is because changes in preparations can alter drug levels and lead to reduced control of seizures. The Adviser said that Dr L should therefore have sought advice from an epilepsy specialist before altering Mr H's medications. She said that having consulted all the relevant people, if those people thought there were no suitable alternatives to Mr H's liquid medication, Dr L should have continued to prescribe Mr H's usual medications regardless of their cost.
78. The Adviser said that refusing to prescribe suitable medication, particularly to a patient with learning disabilities, has the potential to cause harm. She said that Dr L potentially put Mr H at risk of having epileptic seizures by withdrawing and changing his medications. However, the Adviser said that although epileptic

seizures can be fatal (as mentioned by Ms B), the risk of death from an individual seizure is very small.

Our findings

The complaint about Mr H's medication

79. Ms B complains about Dr L's refusal to prescribe her son suitable medication. In order to make a decision about this part of Ms B's complaint, I assess whether Dr L acted in accordance with the Principle of 'Getting it right' (paragraph 18). 'Getting it right' means that Dr L should have acted in line with the *Mental Capacity Act 2005* and its associated Code of Practice (paragraphs 27 to 31) before reaching his decision on Mr H's medication. He also should have acted in line with the GMC guidance set out in paragraphs 37 to 41. Having done this, Dr L's decision not to prescribe Mr H with his usual liquid forms of medication should have been reasonable and based on all relevant considerations. I have taken into account established good practice as outlined by the Adviser in my consideration of this part of Ms B's complaint.
80. Dr L's decision-making regarding Mr H's medication should have been guided by the fact that it had been documented in his GP records that he had learning disabilities and behavioural problems. This should have led Dr L to consider his responsibilities under the *Mental Capacity Act 2005*. In line with the *Mental Capacity Act*, Dr L should have arranged to consult Mr H and his mother so that Mr H's capacity to make an informed decision about his treatment and medications could have been assessed. Dr L should have also liaised with the other clinicians involved in Mr H's care to assess whether he had the capacity to make informed decisions about his own care.

81. If Mr H had been assessed as not having the capacity to make his own decisions, a decision on what would be in his best interests should have been made by Dr L after taking into account Ms B's views and the views of the other clinicians involved in his care. In reaching this best interests decision, Dr L should have considered what medications would least restrict Mr H's basic rights and freedoms. Then, in line with GMC guidance, Dr L should have ensured that the medications he wished to prescribe were appropriate, responsible and in Mr H's best interests by discussing his decision with Ms B and reaching agreement with her on their use. Dr L should have taken account of Ms B's priorities, preferences and concerns when considering the suitability of the medication he wished to prescribe, and the views of Mr H's other clinicians. Further, Dr L should have considered and discussed whether there were any suitable ways of using alternative medication and sought advice on this if necessary. GMC guidance additionally placed responsibility on Dr L to have respected Mr H's dignity. He therefore should have considered whether it was appropriate to prescribe a drug that had to be administered rectally (diazepam) and that might have to be given in public. If Dr L still thought he should change Mr H's medications having taken all the actions outlined above then, in line with established good practice, he should have consulted with an epilepsy specialist before doing so.
82. Dr L initially refused to issue Mr H with a new prescription for midazolam in early 2011. Ms B contacted the Community Nurse, who faxed a request for a new prescription of midazolam to Dr L but he responded with a note saying that *'we will not do this prescription'* and that he would be prescribing rectal diazepam instead.

Dr L spoke to the Community Nurse on 23 March and said that he was not willing to prescribe the drug at a cost of £80 when rectal diazepam was just as good. He wrote to the Community Nurse on 5 April, confirming his decision not to prescribe midazolam and reiterating that *'the cost of midazolam oral liquid is just over £90'* and *'it is no more effective than diazepam rectal tubes [which cost] just under £2'*.

83. Dr L discussed Mr H's medications with Ms B at an appointment on 3 May. He told Ms B he was no longer willing to prescribe her son's medications in liquid form as he had to consider costs. Ms B told Dr L that her son could not take tablets (she subsequently explained to him that this was due to his learning disabilities and that he could physically swallow tablets). However, Dr L noted that there was no clinical reason why Mr H could not swallow tablets, because he was able to eat normally. Dr L discussed his decision with the PCT's prescribing adviser and subsequently issued a new prescription for Mr H in which he had replaced midazolam with rectal diazepam and changed some of Mr H's former liquid medications to tablets.
84. Dr L has always maintained that his decision to not prescribe Mr H liquid medications had been taken following several discussions with the PCT's prescribing adviser, and that he was following their advice and guidance. He maintains that the PCT's prescribing adviser had confirmed that his decision to not prescribe liquid medication to Mr H was correct and supported by the PCT. Dr L maintains that he had followed both national and local guidelines in reaching his decision, although he has been unable to provide those guidelines. He confirmed that he had not refused to prescribe medication to Mr H but had prescribed

suitable, cost-effective medications that, in his view, were suitable for Mr H's needs. The PCT subsequently wrote to Ms B and told her they agreed with her view of the inappropriateness of administering a rectal medication in public in relation to her son's privacy and dignity. They also said that while it is reasonable to prescribe appropriate alternative medications if they are more cost effective, they were firmly of the view that in the case of Mr H '*the alternatives* [that Dr L prescribed] *were not appropriate*'.

85. I find that Dr L's decision not to prescribe Mr H liquid forms of medication was inappropriate because he did not act in line with the *Mental Capacity Act*, GMC guidance and established good practice. Dr L did not consider his responsibilities under the *Mental Capacity Act* in reaching his decision about Mr H's medication. He did not assess Mr H's capacity to make a decision about his own treatments or medications. Nor did he take any of the required actions that could have led him to reach a 'best interests' decision on Mr H's medications.
86. Dr L also did not act in line with GMC guidance because he did not take any of the actions that would have ensured that the medications that he intended to prescribe for Mr H were appropriate, responsible and in his best interests. He did not consider Ms B's preferences and concerns in relation to her son's medication. Indeed, he ignored them. Dr L additionally did not seek the views of clinicians involved in Mr H's care (apart from the Community Nurse, whose request that Mr H should continue with midazolam was dismissed by Dr L) and so could not take these into account in reaching his decision. He also did not consider the potential impact on Mr H's

dignity in prescribing a rectal drug that might have to be administered in public. Consequently, the type of discussion that Dr L should have had with Ms B before changing her son's medication did not happen, and he did not get her agreement to change Mr H's medication. Furthermore, Dr L did not consult an epilepsy specialist before changing Mr H's medication as he should have done. This was not in line with established good practice.

87. Given this series of failings, I find that Dr L's decision to change Mr H's medication was not reasonable because it was not based on all relevant considerations. It was a decision solely based on cost and Dr L's own assumption that because Mr H could physically swallow, it was appropriate to prescribe him tablets. Dr L did not 'get it right' because he did not act in line with the relevant standards in relation to his decision to change Mr H's medications and he did not make a reasonable decision based on all relevant considerations. His actions fell so far below the applicable standards that they constitute service failure.

The complaint about removal from the Practice's list

88. Ms B complains about Dr L's threat to remove her and her son from the Practice's list when she made a complaint about his refusal to prescribe suitable medication for Mr H. To decide on this part of Ms B's complaint, I again assess whether Dr L acted in accordance with the Ombudsman's principle of '*Getting it right*'. What this means is that Dr L should have acted in line with the Practice's GMS Regulations contract (paragraphs 34 to 36) and GMC guidance (paragraph 41).

89. The GMS Regulations contract allows Dr L to remove patients from the Practice's list if he has reasonable grounds and if he complies with the rules set out in that contract. One of these rules is that Dr L must have given a warning to patients, in this case Ms B and Mr H, that they were at risk of removal within the previous 12 months and explained the reasons for this, apart from in exceptional circumstances. The exceptional circumstances that would have allowed Dr L to remove Ms B and Mr H without having first issued a warning are if this would have been harmful to their physical or mental health, put at risk the safety of members of staff or patients at the Practice, or when, in his opinion, it would not otherwise have been reasonable or practical to give such a warning. Additionally, Dr L should have acted in line with GMC guidance and not have threatened to end the doctor-patient relationship solely because Ms B had made a complaint about him or because of the resource implications of treating her or her son.

90. Dr L first suggested that Ms B and Mr H should change their GP practice at the appointment that she had with him on 3 May to discuss her son's medication. Ms B said that Dr L told her at that appointment that she needed to find 'a GP who has bigger budgets, would take [Mr H] on, and be happy to prescribe the medications'. Dr L responded to Ms B's second complaint letter to him on 31 May. He told her that there had been:

'a total breakdown in [the] doctor/ patient relationship and it would be in the [sic] best interest if [Mr H] and you change your general medical practitioner within the next twenty one days, otherwise we as a practice will have no option but to remove you from our list of patients.'

Ms B and Mr H subsequently registered with a new GP practice on 8 July. Dr L told us that at no point was Ms B threatened with removal from the Practice's list, although he did advise her that it was in her and her son's best interests to register with another GP practice. Both Dr L and the PCT confirmed that no formal steps were taken to remove Ms B and Mr H from the Practice's list.

91. I find that Dr L did not act in line with the GMS Regulations contract because he did not give Ms B and Mr H a warning before writing to tell her that she and her son would be removed from the Practice's list if they did not find another GP within 21 days. I have no reason to believe that any of the exceptional circumstances that would have allowed Dr L to remove Ms B and Mr H without a previous warning applied in this case. Dr L believes that he never threatened Ms B with removal from the Practice's list, but that is not the case. His letter of 31 May makes it quite clear that Ms B had 21 days to find another GP practice, otherwise she and her son would be removed. Dr L created a situation where Ms B was left with no option but to find another GP practice, even though she had previously explained that she wished to remain where she was. So while I accept that Dr L did not take any formal steps to remove Ms B and Mr H from the Practice's list, the effect of his actions amounted to removal in all but name. Moreover, Dr L did not act in line with his GMS Regulations contract. Neither did he end his doctor-patient relationship with Ms B and Mr H in line with GMC guidance. This is because the evidence, in particular Dr L's own account, strongly suggests to me that he took his decision solely on the grounds that he found Mr H too expensive to treat and that Ms B had complained about this. I therefore find that Dr L's actions fell so far

below the applicable standard that they constitute maladministration.

Disability discrimination rights

92. I now consider Mr H's rights according to disability discrimination law. Mr H was a person with learning disabilities and Dr L was obliged to consider his needs and whether adjustments needed to be made in order to ensure that he had access to health services designed around his individual needs (paragraphs 19 to 26).
93. It is clear to me that Mr H's rights under disability discrimination law were engaged here and should have been considered in Dr L's decision-making, both in relation to the prescribing of his medication and to any action to remove him from the Practice's list. Dr L told us on 15 November 2012 that he had not taken Mr H's legal rights as a person with disabilities into account. Therefore, I have no hesitation in concluding that in providing care and treatment for Mr H and in subsequently taking action that gave his mother no option but to register him with an alternative GP practice (effectively removing him from the Practice list), the Practice did not have proper regard to its obligations to Mr H under disability discrimination law. I find that the Practice's failings in this respect were so serious that they constitute service failure.

Injustice

94. Ms B said that Dr L's refusal to prescribe her son suitable medication put him at risk, including death. I have found service failure in Dr L's decision not to prescribe suitable medications for Mr H and I agree with her that this put her son at risk. The Adviser said Dr L's decision had the potential to cause Mr H harm as withdrawing and changing his medications

put him at risk of having epileptic seizures. This was undoubtedly an injustice to Mr H, even though I accept that his risk of dying from an individual seizure was very small. It is also evident from Ms B's recollections and account that she was caused a lot of stress and anxiety as a result of Dr L's decision and worried about how she would cope with the impact that it could cause. This was an injustice to Ms B.

95. Ms B said that she was caused significant distress and inconvenience as a consequence of Dr L's threat to remove her and Mr H from the Practice's list. I have found maladministration in Dr L's actions regarding this aspect of the complaint and I can fully see why Ms B was caused significant distress by being made to leave a practice which up until then she had been happy with and for reasons that were unjust and unreasonable. I can also see how this decision caused her immense inconvenience, especially because she was put in the position of having to urgently find appropriate care for her son. These were further injustices to Ms B.
96. I have found that Dr L's decision-making in relation to the prescribing of Mr H's medication and making him withdraw from the Practice's list meant Dr L did not have regard to the Practice's obligations under disability discrimination law and that this was so serious that it constitutes service failure. I have explained in paragraph 26 that a finding of service failure does not always lead to a finding of injustice. However, in this case I find an injustice to Mr H in consequence of the service failure I have identified. His rights were not properly considered by the Practice. If they had been, then different decisions might have been made about the suitability of his medication and whether he should remain on their patient list.

Conclusions

97. Having studied the available evidence and taken account of the information provided by the Adviser, I find that the care and treatment that the Practice provided for Mr H fell so far below the applicable standard that they amount to service failure.
98. I find that the Practice did not have regard to their obligations under disability discrimination law in relation to their decision-making about Mr H's medication and their inappropriate actions which resulted in Ms B having to find a different GP for her and her son. This was also service failure.
99. I find maladministration in the way the Practice made Ms B and Mr H withdraw from their patient list.
100. I considered whether injustices to Ms B and Mr H arose in consequence of the service failure and maladministration and I concluded that they did.
101. I therefore uphold Ms B's complaint about the Practice.

Recommendations

102. I now consider what action should be taken in order to provide a remedy for Ms B and Mr H and ensure that this service failure and maladministration does not recur. When deciding on recommendations, I have taken into account the Principles for Remedy. Three of the Principles particularly relevant to this complaint are:
 - *'Being customer focused'* – which includes apologising for and explaining the poor service;

- *'Putting things right'* – which includes compensating the complainant appropriately; and
- *'Seeking continuous improvement'* – which includes using the lessons learnt from complaints to ensure that poor service is not repeated.

103. I recommend that within one month of the date of this final report, the Practice should:

- write to Ms B to acknowledge their failings in the care and treatment of Mr H, and also in the way that they made Ms B and Mr H find a different GP when they did not want to move from the Practice. They should acknowledge, and apologise for, the impact that these failings had on Ms C and her son (paragraphs 94 to 96); and
- pay Ms B (on behalf of Mr H) the sum of £500 in recognition of the fact that Mr H was put at risk by the service failure that I have identified and that he suffered a further injustice in that his rights as a disabled person were not properly considered by the Practice. The Practice should also pay Ms B a further sum of £500 to remedy the injustices of stress, anxiety, significant distress and inconvenience arising from the service failure and maladministration that I have identified. The Practice should pay Ms B a total of £1,000.

A copy of the letter should be sent to us, with notification that the payment has been made.

104. I also recommend that Dr L reflects on the findings in this report and works with his responsible officer to agree and implement a plan to address and remedy the failings that we have identified. Specifically, the plan should outline how Dr L is going to improve his awareness of his responsibilities, both legal and professional, to patients with disabilities. The plan should also outline what actions Dr L has taken (or intends to take) to improve his understanding of his contractual and professional obligations when making decisions to remove patients from his list.

105. This plan should form the basis of a discussion with Dr L at his next appraisal to establish whether he has made the necessary improvements to his practice. A copy of this plan should be sent to us within three months of the date of the final report. Furthermore, the Practice should write to Ms B and us once Dr L has had his appraisal to confirm that he has made the agreed improvements to his practice.

Final remarks

106. In this report I have set out our investigation, findings, conclusions and decision with regard to Ms B's concerns.
107. I hope this report will provide Ms B with the explanations she seeks. I also hope she will be reassured that lessons will be learnt and the learning shared as a result of her complaint, so that others will be less likely to suffer the same experiences in future.

Parliamentary and Health Service Ombudsman

Millbank Tower
Millbank
London SW1P 4QP

Tel: 0345 015 4033

Fax: 0300 061 4000

Email: phso.enquiries@ombudsman.org.uk

www.ombudsman.org.uk

Follow us on



If you would like this report in a different format, such as DAISY or large print, please contact us.



information & publishing solutions

Published by TSO (The Stationery Office) and available from:

Online

www.tsoshop.co.uk

Mail, telephone, fax and email

TSO

PO Box 29, Norwich NR3 1GN

Telephone orders/general enquiries: 0870 600 5522

Order through the Parliamentary Hotline Lo-Call 0845 7 023474

Fax orders: 0870 600 5533

Email: customer.services@tso.co.uk

Textphone: 0870 240 3701

The Houses of Parliament Shop

12 Bridge Street, Parliament Square,

London SW1A 2JX

Telephone orders/general enquiries: 020 7219 3890

Fax orders: 020 7219 3866

Email: shop@parliament.uk

Internet: <http://www.shop.parliament.uk>

TSO@Blackwell and other accredited agents

ISBN 978-0-10-298643-3



9 780102 986433