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[Title page]

## Why a Charter for Best Practice for NHS wig provision?

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### Key words

Wig, wigs, best practice, charter, alopecia

### Declaration of interest

[XXXXXXXXXX]

### Summary

Dermatological hair loss is a devastating condition and not ‘just’ cosmetic. Wigs are recommended as a treatment by the British Association of Dermatologists (BAD) and NICE; however, wig provision is not equal in England. Alopecia UK understands what is ‘Best Practice’ for wig provision and aims for this to be adopted. Alopecia UK is proud to announce that it is working with NHS England and NHS Improvement to develop a ‘Best Practice wigs charter’, with input from key stakeholders, to eliminate variations in care and improve care.

### Key points

1. Hair loss is devastating and more than just cosmetic
2. Wigs are recommended as a treatment by BAD and NICE
3. Wig provision is not equal in England
4. Alopecia UK has heard what constitutes ‘Best Practice’ and aims for this to be widely adopted
5. Alopecia UK is working with NHS England and NHS Improvement to develop a ‘Best Practice wigs charter’ to improve patient care

## [MAIN PAPER]

### Introduction

*“A wig is a necessary orthotic to help enable a person with hair loss to have an equitable life in society.”* Professor Anthony Bewley, 2021

For many people, hair is a central aspect of their appearance, and hair loss often has a profound negative impact on self-esteem, body image and confidence.<sup>1</sup> Coping with the impact of dermatological hair loss (alopecia) depends on an individual’s ability to deal with an altered body appearance and their perception of themselves.<sup>2</sup> Hair loss has been likened to bereavement or loss of a limb, emphasising that the impact extends beyond the physical body to self-confidence, self-esteem and identity.<sup>3</sup>

A wig enables an equitable life, in school, college, at work and socially.<sup>1</sup> Many people choose to wear wigs to manage the social and psychological consequences of living with alopecia. Evidence suggests that wigs provide a useful strategy for managing negative reactions from others and give patients with alopecia the confidence to engage in society.<sup>4</sup>

The British Association of Dermatologists (BAD) (2012 guidelines on alopecia areata) suggested that wigs should be offered as a treatment option for people living with alopecia areata,<sup>1-2</sup> which NICE has agreed with.<sup>5</sup> However, key findings in two surveys suggest that wig provision within NHS England is very variable, which leads to inequitable access for patients with alopecia across England.<sup>1,6</sup> Individuals in England often struggle to access wigs via the NHS, and funding is withdrawn due to changes in NHS Trusts' policies on wig provision and affording wigs privately is a challenge for many.<sup>1</sup> Patients also worry about being able to afford wigs.<sup>4</sup>

Alopecia UK patient research has highlighted what is important to patients, and how their needs could best be addressed.<sup>1</sup> A Best Practice Charter for NHS wig provision by prescription or voucher would help improve services around England and relieve pressures on patients and the NHS. Alopecia UK understands that there are also differences across the four UK nations, aligned to prescription structures, but this review focuses on England.

Note: Most data cited herein originates from three patient surveys/reports: one survey prepared for Alopecia UK by the Centre for Appearance Research (CAR) (n=361 in the UK of which 83% were based in England), referred to as the CAR report,<sup>6</sup> one report undertaken by Alopecia UK commissioned in response to the concerns regarding wig provision raised by individuals contacting Alopecia UK, undertaken in 209 CCGs across England in 2017, referred to as the AUK 2017 report,<sup>1</sup> and one cross-sectional survey sent by email to the Alopecia UK mailing list and advertised on social media in 338 patients in 2017, referred to as the AUK 2017 survey.<sup>4</sup>

## **[HEADER] Taking dermatological hair loss seriously**

**There are many causes of dermatological hair loss (alopecia), but it's not 'just' hair loss and it's not 'just cosmetic'. Diagnosis, treatment and wig provision vary across England, and Best Practice should be implemented.**

Alopecia is the medical term for baldness, or the partial or complete absence of hair from areas of the body where it normally grows. Males and females of any age and hair colour can have alopecia.<sup>7</sup>

In the CAR report, the main causes of alopecia were:<sup>6</sup>

- Alopecia areata (AA) (35%)
- Alopecia universalis (34%)
- Alopecia totalis (12%)
- Frontal fibrosing alopecia (9%)
- Androgenetic alopecia (6%)
- Lichen planopilaris (3%)
- Other (1%)

Living with alopecia involves unpredictable, sometimes rapid hair loss, and people describe feelings of shock, loss, trauma and disrupted identity.<sup>3</sup> In an online qualitative survey of 95 people with alopecia, hair loss was emotionally devastating for many, and could lead to depression, anxiety and, in some instances, suicidal thoughts. Hair loss was frequently likened to bereavement or loss of a limb.<sup>3</sup> In the AUK 2017 survey, clinically significant levels of anxiety were reported by 35.5% of participants and clinically significant levels of depression were reported by 29%.<sup>4</sup>

A systematic review of 1,271 individuals concluded that alopecia could cause devastating emotions and have a negative impact on self-esteem, body image and confidence.<sup>8</sup> Many people describe being told it is 'only hair' by healthcare professionals, which deepened distress.<sup>3</sup> In the CAR report, of the 201 respondents who reported seeing any NHS staff in the past two years about their hair loss, 25% reported that staff had referred to hair loss as a "cosmetic issue" or "cosmetic problem".<sup>6</sup> This fails to recognise the significant psychological suffering that can result from hair loss.<sup>1</sup> In fact, alopecia has been associated with higher levels of perceived stigmatisation than concealable conditions, such as mental health conditions.<sup>9</sup>

NICE recommends that patients with alopecia are offered the provision of psychological support if needed and appropriate.<sup>5</sup> However, currently, no tailored support exists to support people with alopecia within the NHS<sup>1</sup> and implementing best practice would help improve this.

**Quote from person with alopecia**

*"People often say 'it is only hair', 'it is not a life-threatening condition' but personally I do not think that anyone can appreciate just how massive losing your hair is unless or until it happens to you. They need to understand how massive it is and how the condition often brings feelings of huge depression and suicidal thoughts."*<sup>3</sup>

**[HEADER] The need for equitable supply of wigs in England**

**Despite wigs being an important treatment for people living with alopecia, many people experience difficulties accessing wig prescriptions via the NHS; schemes around England should be levelled up and Best Practice should be implemented.**

Wig provision can aid enormously with the trauma a person with alopecia is dealing with.<sup>1</sup> In the CAR report, out of 292 respondents, 77% said they have worn a wig at some point. The mean number of wigs per year was 1.4. Of the respondents, 75% wore their wig all the time or for most of the time whilst they were in public. This suggests that people who have worn wigs wear them frequently, with only 12% wearing them only rarely or for special occasions.<sup>6</sup> Table 1 shows wig use in the AUK 2017 survey.<sup>4</sup>

**Table 1. Wig use of participants (n=338)<sup>4</sup>**

How often do you wear a wig?	%
Never	24
Occasionally	17
Most of the time	26
All the time (excluding the night)	44
All the time (including the night)	6

In the AUK 2017 survey, 86.7% reported wearing a wig to socialise, and 66.3% of respondents reported they would not feel confident leaving the house without a wig. This suggests there may be wider economic implications if wigs are not a readily available or financially viable option for people living with alopecia.<sup>4</sup>

Differences exist across England in terms of whether wigs are supplied by a voucher system and/or a prescription, the number of wigs supplied per year (0-4/year) and the financial limit specified.<sup>10</sup> In the AUK 2017 survey, the majority of people did not obtain NHS wig prescriptions (50.6%) out of which 11.2% of participants had been told that they were not eligible and 22.5% had never enquired about it.<sup>4</sup> The disparity between NHS Trusts suggests that some people cannot access any funding for wigs, whilst others may receive up to two wigs a year.<sup>1</sup>

In the CAR report, of the 215 respondents who reported wearing a wig at some point, Table 2 shows how they access wigs.<sup>6</sup>

**Table 2. Description of NHS wig provision (n=215)<sup>6</sup>**

<b>Selected statement to describe state of NHS provision</b>	<b>%</b>
Currently access NHS wigs	34
Never offered NHS wigs	17
Offered NHS wigs but opted to purchase privately	6
Stopped accessing NHS wigs because provision changed for worse	14
Want/need human hair unavailable via NHS	5
NHS wigs provision stopped	4
Told no help with wigs available	2
Told hair loss insufficiently severe for NHS wig	1
Other	16

Of these 215 respondents, 45% answered a subsequent question which asked why they chose to purchase wigs privately rather than through the NHS (Table 3).

**Table 3. Reasons why respondents chose to purchase wigs privately (n=96)<sup>6</sup>**

<b>Selected reason for why respondents chose to purchase wigs privately</b>	<b>%</b>
Lack of quality	35
Poor experience of wig provision process	29
Lack of quantity	20
Couldn't access preferred wig type	19
Dissatisfied with contracted wig supplier	19

In the CAR report, of the 143 individuals who answered a question about the type of wig they access through the NHS, 78% reported using synthetic fibre/acrylic wigs, 15% reported using human hair wigs and 7% said they used both wig types. Fifty six percent reported paying a prescription charge for wigs provided through the NHS, 36% felt the process to receive an NHS wig was inaccessible, to the point where 16% had given up trying.<sup>6</sup> Also, when asked whether their NHS organisation offers a voucher system for wig provision (i.e., gives vouchers in exchange for wig(s) with a supplier), 66% said they haven't been provided with vouchers, 19% said they had vouchers but still paid a prescription charge, and 16% said they had vouchers and did not need to pay a charge.<sup>6</sup>

Further funding cuts in dermatology could mean more patients have difficulties accessing wigs, which may have significant psychosocial consequences for people living with alopecia.<sup>4</sup> In the AUK 2017 report, one Trust had recently withdrawn their funding for wigs, 31/68 (46%) of Trusts had no wig policy in place, and 13/68 (19%) used the Individual Funding Request process for all wig prescriptions. Six Trusts of 68 (9%) responded that alopecia is: *“Considered a cosmetic issue and therefore wigs are not funded”*.<sup>1</sup>

More clarity is needed for patients on how to obtain a prescription and the process between primary and secondary care should be simplified. Poor communication between the NHS to patients about

where and how to obtain their prescription causes real frustration and anxiety at a time when the patient is feeling vulnerable<sup>10</sup> and harms patient care.<sup>6</sup>

**Trusts should be encouraged to set up a Best Practice wig policy that will smooth the transition between primary and secondary care services, 'level up' wig supply across England, and offer patients a valuable treatment that many cannot currently access.**

#### **Quotes from people with alopecia**

*"More clarity is needed for patients on how to obtain a prescription and the whole process should be simplified."*<sup>10</sup>

*"Some hospitals have now stopped offering wigs when it should be the same for everyone; a wig is a prosthetic that should be available to all with medical hair loss."*<sup>10</sup>

**[HEADER] A reasonable expectation for an appropriate and timely number of wigs per year**

**Wigs are closely linked with improved mental health, yet access to NHS wigs remains a challenge for many.**

Despite wigs being an important coping strategy for people living with dermatological hair loss, many people experience difficulties accessing wig prescriptions via the NHS.<sup>4</sup>

NICE recommends that patients with AA are offered the option of using hairpieces and wigs if needed and appropriate.<sup>5</sup> However, feedback from people living with AA suggests that many people are advised they are not eligible for wigs and/or are not offered two wigs.<sup>1</sup>

Synthetic acrylic wigs are the most affordable option. Monofilament acrylic wigs are constructed to give the appearance of hair growing from the scalp; they are light, look natural, and come in a variety of colours, lengths, and styles. However, all synthetic wigs become damaged near heat such as opening oven doors and patio heaters and, if worn daily, will need replacing every 3-4 months to maintain the appearance of the acrylic fibres in good condition and the illusion of hair.<sup>2</sup> Yet, the NHS states that synthetic wigs last 6 to 9 months.<sup>11</sup>

Human hair looks very natural and will last longer if kept in good condition, typically 1-2 years. However, the NHS policy on entitlement for a prescription for human hair wigs is only available to patients who are allergic to acrylic or who have a skin condition made worse by acrylic.<sup>2</sup>

In the AUK 2017 survey, the most common type of wigs worn by participants were acrylic (acrylic monofilament 39.3%, acrylic lace front 27.5%, and acrylic wefted wig 14.8%).<sup>4</sup> Of the participants who claimed NHS wig prescriptions (46.1%), 11.5% claimed one per year, 26% claimed two per year, and 8.6% claimed more than two each year.<sup>4</sup>

In the CAR report, 74% of 160 respondents agreed that they felt anxiety about not being able to continue to access wigs via the NHS or being able to afford to purchase them privately in the future, and 32% of 130 respondents felt there should be a reduction in financial barriers to accessing the service.<sup>6</sup>

In the AUK 2017 report, of participants who purchased wigs by NHS prescription (49%), 28.1% reported being unable to afford their wig privately. The majority reported worry about affording new wigs (65.1%) and those who worried about wearing a wig reported significantly higher levels of depression, anxiety, and social anxiety. This is a concerning finding given that more and more people are contacting Alopecia UK to report their wig funding being withdrawn.<sup>1</sup>

The introduction of Best Practice wig services, taking into account a person’s degree of anxiety and not just the percentage hair loss when determining who is eligible for NHS wigs and the number permitted, would help pressures on patients and the NHS.

**Quotes from people with alopecia**

*“I don’t think it’s reasonable to expect 2 synthetic wigs to last for a year. They are not built to last this long with daily wear.”<sup>6</sup>*

*“With 2 wigs/year, by the end of the year, the wigs are no longer fit for purpose.”<sup>10</sup>*

**[HEADER] Offering the appropriate choice and quality of wigs**

**Access to NHS wigs for people with dermatological hair loss in England needs to be of a suitable quality and choice, as well as being timely.**

The AUK 2017 report highlighted that wig provision across England varies considerably. The accessible quantity and type of wigs varies considerably between different NHS Trusts/CCGs.<sup>1</sup>

In most cases, Alopecia UK understands that a patient in England needs to see a Consultant Dermatologist to be assessed and given a wig prescription. We also hear that referrals to dermatology are limited and the waiting list can be up to a year. We recommend more communication between secondary and primary care so that there can be timely (within 3 months) wig provision to enable the patient’s confidence in managing their alopecia and its impact on their life.

Choosing to wear a wig can be an overwhelming experience, due to the variety of different options and suppliers.<sup>2</sup> People with alopecia prefer to have direct contact with their NHS wig consultant and prefer to have it fitted in a discreet environment, away from the main hospital setting.<sup>10</sup> Face-to-face wig clinics are beneficial as they offer patients time, confidence and, advice at such a traumatic time. It is important that suppliers chosen by NHS England provide a variety of wigs to meet patient needs, including consideration of age, hair colour, and textures for BAME populations. In the CAR report, satisfaction with wigs is shown in Table 4.<sup>6</sup>

**Table 4. Satisfaction with quality and quantity of NHS wigs, and NHS wig supplier<sup>6</sup>**

Satisfaction level	Quality (n=113), %	Quantity (n=109), %	Wig supplier (n=104), %
Very satisfied	23	22	41
Fairly satisfied	36	19	27
Neither satisfied nor dissatisfied	15	19	12
Fairly dissatisfied	14	23	14
Very dissatisfied	12	17	15

Further data highlight satisfaction ratings for these three aspects of NHS wig provision depending on whether respondents were from NHS Scotland or NHS England (Table 5) (note there were a small number of respondents from Scotland).<sup>6</sup>

**Table 5. Satisfaction with quality and quantity of NHS wigs, and NHS wig supplier (England vs Scotland)<sup>6</sup>**

Satisfaction ...	England	Scotland
<b>with the quality of wigs</b>	54% 'very' or 'fairly' satisfied (n=81)	76% 'very' or 'fairly' satisfied (n=25)
	26% 'very' or 'fairly' dissatisfied (n=81)	24% 'very' or 'fairly' dissatisfied (n=25)
<b>with the quantity of wigs</b>	36% 'very' or 'fairly' satisfied (n=78)	58% 'very' or 'fairly' satisfied (n=24)
	43% 'very' or 'fairly' dissatisfied (n=78)	25% 'very' or 'fairly' dissatisfied (n=24)
<b>with the wig supplier</b>	58% 'very' or 'fairly' satisfied (n=83)	87% 'very' or 'fairly' satisfied (n=23)
	27% 'very' or 'fairly' dissatisfied (n=83)	13% 'very' or 'fairly' dissatisfied (n=23)

In the CAR report, of 151 individuals, 42% reported that they were not offered a choice of wig supplier through the NHS; 15% felt that NHS wig provision was not levelled-up, 46% felt that there was inadequate provision of NHS wigs for them, 31% experienced supplier issues with their NHS wig provision, and 32% felt that the restricted choice of sometimes poor-quality wig suppliers was inadequate.<sup>6</sup>

In the AUK 2017 report, of 91 people who responded to the question, 35% thought the lack of supplier choice was the biggest challenge with wig provision in England.<sup>1</sup>

NICE recommends that patients with AA are offered the option of using hairpieces and wigs if needed and appropriate.<sup>5</sup> Yet some hospitals have now stopped offering wigs altogether.<sup>12</sup>

**An NHS Best Practice wig service would ensure that all NHS Trusts/CCGs/ICSs understand the value of wigs to patients with dermatological hair loss and do their best to provide a patient-centric service, offering face-to-face wig consultation, a selection of suppliers, and a choice of high-quality wigs which meet the needs of the patients, regardless of sex, age, natural hair colour, and ethnicity.**

**Quotes from people with alopecia**

*"The NHS wigs look like wigs, so I always imagine people are saying 'Look at her wearing that stupid wig'. I only go out if absolutely necessary and avoid public places as often as I can. I FEEL LIKE A FREAK."*<sup>4</sup>

*"People with alopecia prefer to have direct contact with their NHS wig consultant and prefer to have it fitted in a discreet environment, away from the main hospital setting."*<sup>10</sup>

**Conclusions**

Hair loss is emotionally devastating for many people.<sup>3</sup> The British Association of Dermatologists and NICE suggest that wigs should be offered as a treatment option for people living with alopecia.<sup>1-2,5</sup>

However, wig provision within NHS England is very variable, which leads to inequitable access for alopecia patients across England.<sup>1</sup> Differences exist in how wigs are supplied (prescription/voucher), and in the quality, choice, and number offered.<sup>6</sup> Through patient research and social media, Alopecia UK hears what is considered to be 'Best Practice' for wig provision and acknowledges the dermatology departments who continue to promote appropriate wig provision. Alopecia UK aims for this to become more widespread, eventually eliminating current variations in care.

Alopecia UK is proud to announce that it is currently working with NHS England and NHS Improvement to develop a 'Best Practice wigs charter', with input from key healthcare professional associations, as well as wig suppliers and patients.

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