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# What Do Patients With Glaucoma See? Visual Symptoms Reported by Patients With Glaucoma

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Abstract: Background: Vision loss from glaucoma has traditionally been described as loss of "peripheral vision." In this prospective study, we aimed to improve our clinical understanding of the visual symptoms caused by glaucoma by asking patients specific detailed questions about how they see. Methods: Patients who were clinically diagnosed with various types and stages of glaucoma were included. All had a comprehensive ocular examination, including Octopus visual field testing. Patients were excluded if they had other ocular conditions that affected their vision, including cornea, lens or retina pathologies. Patients responded to an oral questionnaire about their visual symptoms. We investigated the visual symptoms described by patients with glaucoma and correlated the severity of visual field loss with visual symptoms reported. Results: Ninety-nine patients completed the questionnaire. Most patients (76%) were diagnosed with primary open-angle glaucoma. The most common symptoms reported by all patients, including patients with early or moderate glaucoma, were needing more light and blurry vision. Patients with a greater amount of field loss (Octopus mean defect >+9.4 dB) were more likely to report difficulty seeing objects to one or both sides, as if looking through dirty glasses and trouble differentiating boundaries and colors. Conclusions: Vision loss in patients with glaucoma is not as simple as the traditional view of loss of peripheral vision. Needing more light and blurry vision were the most common symptoms reported by patients

Key Indexing Terms: Glaucoma; Visual symptoms; Peripheral vision; Visual field; Contrast sensitivity. [Am J Med Sci 2014;348(5):403–409.]

C laucoma is one of the leading causes of blindness worldwide with a prevalence of over 2 million in those aged 40 years and older in the United States. <sup>1-3</sup> As the U.S. population continues to age, the prevalence of glaucoma is projected to reach 3 million by the year 2020.<sup>3</sup>

Vision loss due to glaucoma has traditionally been described as loss of "peripheral vision"; that is, loss of vision at the outer edges.<sup>4-7</sup> Current educational Web sites for the general public illustrate the loss of vision in glaucoma as

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"tunnel vision" or as if one is "looking through a straw" (Figure 1).<sup>8</sup> However, glaucomatous vision loss may involve not only narrowing of the visual field (VF) but also deterioration in the quality of vision.<sup>9-13</sup> Several studies have demonstrated that in addition to VF losses, deterioration of contrast sensitivity and color discrimination can occur early in the disease process.<sup>10-12</sup> Additionally, patients may report other visual symptoms due to glaucoma, such as blurriness, dimness or cloudiness.

Loss of peripheral vision for 1 eye indicates diminished vision toward the edges of the VF of that eye (Figures 2A and 2B). However, anecdotally, most people with binocular vision consider their peripheral vision to be sight to the right and left side of their body (Figure 2C). Patients do not consider nasal visual loss as "peripheral." Temporal areas of the VFs are areas most people consider peripheral vision, yet the temporal areas of the VF are lost late in the course of glaucoma. <sup>14,15</sup> These linguistic discrepancies further complicate the description of peripheral visual loss in patients with glaucoma.

The goal of this prospective study was to assess the visual symptoms described by patients with glaucoma. Currently, there are no objective methods to assess what patients experience subjectively. Although quality of life measures address physical symptoms, <sup>16,17</sup> there are no tools to consider visual symptoms in detail. Our study aimed to improve our understanding of how glaucoma affects vision from the patients' point of view by asking specific detailed questions about how they see. A secondary objective of the study was to correlate severity of VF loss with visual symptoms reported.

#### **METHODS**

#### **Study Participants**

All patients in this study were established patients at the Glaucoma Service of Wills Eye Hospital. Incoming patients returning for an office visit between July 2011 and December 2011 were screened before their office visit to determine their eligibility for study inclusion. During this time period, all eligible patients were approached (n=102) and 3 patients refused to participate. Written informed consent was obtained from all study participants (n=99). The Research Ethics Board of Wills Eye Hospital approved this study following the principles of the Declaration of Helsinki.

Inclusion criteria required patients to be clinically diagnosed with glaucoma at a previous visit at least 1 year before. Patients with primary open-angle glaucoma, normaltension glaucoma, pseudoexfoliative glaucoma and pigmentary glaucoma were included in the study. A diagnosis of glaucoma was based on characteristic optic nerve damage on slit-lamp examination (defined as definite notch in the neuroretinal rim or absence of neuroretinal rim not due to another known cause) with corresponding VF defects. 18

Patients were excluded if they had other ocular conditions, trauma or surgeries that affected their vision, such as

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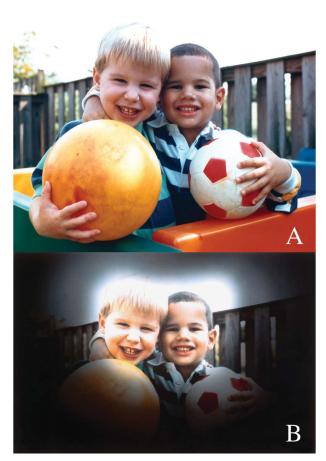


FIGURE 1. (A) Patient view with normal vision. (B) Patient view with glaucoma. S Loss of vision in glaucoma has been traditionally described as "tunnel vision" or as if "looking through a straw" (courtesy: National Eye Institute and National Institutes of Health).

cornea, lens or retina pathologies. Patients with previous glaucoma or cataract surgeries were included. However, patients who had surgeries within the past year as well as previous cornea or retina surgeries were excluded. Other exclusion criteria included patients with extreme refractive errors such as high myopia (-6.0 or higher), high hyperopia (+6.0 or higher) or astigmatism, acute angle-closure glaucoma, ocular hypertension, history of stroke, neurologic pathology or insufficient understanding of English that would prevent the patient from participating in the study. Cataracts and intraocular lens opacity were graded based on clinical judgment of nuclear sclerosis severity. To reduce the effects of cataracts or intraocular lenses on vision, patients were excluded if they had > +1 nuclear sclerosis, > +1 posterior capsule opacification or multifocal intraocular lenses in either eye.

#### **Ouestionnaire**

A questionnaire was developed based on the most frequent visual symptoms mentioned by patients in previous studies on visual disability in glaucoma<sup>17,19,20</sup> as well as the clinical experience of a glaucoma specialist (G.L.S.). An initial version of the questionnaire was administered to 8 patients (not included in this study). After interviewer debriefings, modifications to question wording was made for 2 questions to reduce confusion for pa-

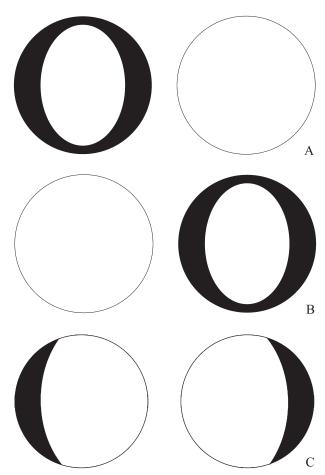


FIGURE 2. (A) Loss of "peripheral vision" can use an eye or a person as its central reference point. Loss of peripheral vision for the left *eye* means loss of vision toward the edges of the VF of that eye. (B) The same is true for the right eye. (C) Loss of peripheral vision for the *person* implies loss of sight off to the person's sides, either the right and left side (as shown) or above and below. VF, visual field.

tients. The final version of the questionnaire consisted of 25 "yes or no" as well as 3 open-ended questions (Appendix).

A research technician administered the questionnaire orally to all study participants. A second research technician administered the same questionnaire for a second time, a minimum of 15 minutes later, to test for agreement. The interviewers read the questions out loud as they stand in the written form of the questionnaire. Patients were asked to report on the presence of their visual symptoms after correction for their refractive error and astigmatism. Patients were asked to use their current spectacles or contact lenses at the time the questionnaire was given. Trial lenses were available for patients if they did not have an updated refraction.

## **Visual Assessment**

After the questionnaire was completed, all patients had a comprehensive ocular examination, including slit-lamp examination and fundoscopy. VFs were tested monocularly for both eyes using Octopus 900 Static Perimetry 24-2 SITA standard (Haag-Streit, Mason, OH). The best-corrected visual acuity (BCVA) was measured using Snellen's chart at 20 feet.

TABLE 1. Characteristics of 99 questionnaire respondents

Characteristic		No. of participants
Age	Mean (SD) = $70 (13.5)$	99
Gender	Female	54
	Male	45
Race	White	66
	African American	29
	Other	4
MD category	Early (MD, $-0.7$ to $+4.4$ dB)	47
	Moderate (MD, +4.5 to +9.4 dB)	26
	Advanced (MD, +9.5 to +15.3 dB)	14
	Severe (MD, +15.4 to +23.1 dB)	7
	End stage (MD, >23.2 dB)	5
Type of	Primary open-angle glaucoma	75
glaucoma	Chronic angle-closure glaucoma	14
	Pseudoexfoliative glaucoma	6
	Pigmentary glaucoma	4
Lens status	No nuclear sclerosis or other apparent lens change	46
	Trace nuclear sclerosis	13
	+1 Nuclear sclerosis	33
	+1 Posterior capsular opacity	7

## **Statistical Analysis**

The study concluded at the end of December 2011, at which point, 99 patients had been interviewed. All 99 patients were stratified by the severity of glaucomatous damage into 1 of 5 categories using the Octopus mean defect (MD) score of their better eye: -0.7 to +4.4 dB (early glaucoma), +4.5 to +9.4 dB (moderate glaucoma), +9.5 to +15.3 dB (advanced glaucoma), +15.4 to +23.1 dB (severe glaucoma) and >23.2 dB (end-stage glaucoma). This staging system was derived from a panel of glaucoma specialists who used published literature to convert the Humphrey's threshold values to Octopus values.  $^{18,21,22}$  We looked at differences between age, gender and race between the 5 MD categories with analysis of variance and Pearson's  $\chi^2$  tests. The association between MD category and questionnaire responses was assessed using the Cochran-Armitage trend test. The Cochran-Armitage trend test assesses for the presence of an association between a variable with 2 categories (patient response) and a variable with multiple categories (MD categories). We used Fisher's exact test to assess symptoms by MD  $\leq$  +9.4 and MD > +9.4 dB. The association between location of VF defect and visual symptoms reported was also determined using Fisher's exact test. Data was analyzed using SAS Analytics Pro statistics software, version 9.2 (SAS Institute, Inc, Cary, NC).

We transcribed the responses from the open-ended questions looking for any descriptor of visual symptoms. Words such as blurry, blurred and blurriness were all considered to be derived from 1 descriptor, blur. When descriptors such as foggy, blurry and hazy were used, they were considered different descriptors. The frequency of descriptors was tallied.

The location of all VF defects was documented by better eye and worse eye. In addition, we compared the agreement of laterality of field loss and the laterality of symptoms reported. When the person reported difficulty seeing to the left with corresponding left-sided field loss, the person was listed as "field and symptoms" agree. When the person reported difficulty seeing to the left and the VF loss was right sided, the person was listed as "field and symptoms" disagree and vice versa. If the person did not report difficulty seeing to one or both sides and did not have lateral field defects, then the person was listed as "field and symptoms" agree.

## **RESULTS**

A summary of patient characteristics is displayed in Table 1. The average number of years diagnosed with glaucoma was 8.4 years. For each MD group, the average number of years diagnosed with glaucoma was 7.7 years for early, 7.6 years for moderate, 8.9 years for advanced, 8.5 years for severe and 17.2 years for end stage. There were no age or gender differences between the 5 MD groups, but race significantly varied (Table 2). Most patients (75%) had a BCVA of 20/20 in their better eye, and 91% of patients had a BCVA of 20/30 or better.

When considering all patients, 92% reported at least 1 visual symptom after correction for their refractive error and astigmatism. Table 3 displays the most common symptoms reported by all patients. For patients with early or moderate glaucoma without cataract (n = 33), the most common symptoms reported were needing more light (58%), blurry vision (52%) and seeing glare (52%).

For the 8 patients (8%) who did not report any visual symptoms, the average MD of the better eye was 4.5 dB (range, 0.9–7.9 dB). From the VFs of the better eye, 4 patients had mild generalized field depression, 3 had an arcuate scotoma and 1 had a paracentral scotoma. All patients had early or moderate glaucoma by MD category and a BCVA  $\leq 20/40$ .

Patients were asked the open-ended question: "How is your vision different?" from either 5 or 15 years ago. The most common response was "blurriness" (15%). Although we received similar comments from other patients, 1 patient expressed, "The world seems more blurry. It's just not real clear. Things used to be crisper". Another patient described, "It's like looking underwater." Other common responses to describe the change in vision were "fuzzy" (6%), "less clear" (6%), "harder

TABLE 2. Age, gender and race by MD category

	-	MD category				
	Early	Moderate	Advanced	Severe	End stage	P
Age	67 (SD: 13)	76 (SD: 13)	68 (SD: 10)	78 (SD: 14)	81 (SD: 13)	0.13
Gender (female:male)	23:24	15:11	8:6	4:3	4:1	0.21
Race (white:other)	37:10	14:12	9:5	6:1	1:4	$0.02^{a}$

 $<sup>^{</sup>a} P < 0.05.$ 

MD, mean defect.

TABLE 3. Most common visual symptoms reported by all patients

Symptom	% Reported
Needing more light	57
Blurry vision	55
Seeing glare	46
Difficulty seeing objects off to both sides	36
Letters appearing faded when reading	30
Difficulty seeing objects off to left side	27
Seeing too much light	26
Area(s) darker or missing	26
Seeing as if looking through dirty glasses	25
Difficulty seeing objects off to right side	24
Seeing as if looking through clouds	23

to read" (5%), "hazy" (4%) and "cloudy" (2%). No patient complained of "tunnel vision" or loss of side vision. No patient provided novel information from the open-ended questions that were not addressed in the questionnaire.

Patients in a higher MD category were more likely to report 6 visual symptoms, shown in Table 4. Compared with patients with early or moderate glaucoma, those with field loss worse than MD of +9.4 dB were significantly more likely to report these 6 symptoms ( $P \le 0.05$ ).

Of the 198 eyes in the study, 196 were diagnosed with glaucoma. Two participants had unilateral glaucoma. Of the 196 eyes, there was agreement between laterality of field loss and laterality of symptoms 68% of the time, and no agreement 20% of the time. For 24 eyes (12%), it was not possible to determine whether there was agreement between laterality of field loss and laterality of symptoms reported.

Table 5 provides a detailed account of the location of VF defects by better eye and worse eye. There was no significant association between location of VF and symptoms reported for the 3 most common symptoms (P = 0.89).

Patients were administered the same questionnaire twice, a minimum of 15 minutes apart. The average percent agreement was 0.89 (range, 0.73–1) between the 2 responses, and the average Kappa for agreement was 0.60.

#### **DISCUSSION**

The purpose of this study was to determine how glaucoma affects vision from patients' point of view. We administered a questionnaire to patients with glaucoma to determine visual symptoms reported, and we correlated the severity of VF loss with symptoms reported.

In contrast to the traditional view of glaucoma, 4-7 loss of peripheral vision was not the most common symptom reported. Needing more light and blurry vision were the most common symptoms reported, and these symptoms were not associated with any specific area of VF defect. These symptoms may be more consistent with loss of contrast sensitivity than field loss. Decreased contrast sensitivity is an established finding in patients with glaucoma, which may be contributing to reduced image quality. 11,23-25 The pathological thinning of the nerve fiber layer that occurs in glaucoma may explain why blurry vision was one of the most commonly reported symptoms. 26,27

Other symptoms reported by more than 25% of patients in our study included seeing glare, letters appearing faded when reading, seeing too much light or seeing as if looking through dirty glasses. These reported symptoms suggest that decreased image quality, not simply VF loss or "tunnel vision," plays an important role in glaucoma. No patient in this study reported "tunnel vision." Crabb et al<sup>28</sup> also found that "tunnel vision" does not accurately describe what patients with glaucoma perceive. They asked patients with primary open-angle glaucoma to select 1 image of 6 choices that most closely represented their perception of their VF loss, and the most frequently selected images were blurred patches and missing patches. No patient in their study selected the image with a distinct black tunnel or black patches. <sup>28</sup>

Along with a decrease in the quality of vision, our study found that the fourth, sixth and ninth most common complaints were related to difficulties seeing to 1 or both sides. There was an agreement between laterality of field loss and laterality of symptoms reported approximately 65% of the time, suggesting that field loss plays a role in difficulty seeing to the sides. However, most patients in our study did not have a constricted VF. There was no agreement between laterality of field loss and laterality of symptoms in 20% of eyes, suggesting that it may not be simply the VF accounting for symptoms reported. Deterioration of image quality or reduced contrast sensitivity

TABLE 4. Association between MD category and visual symptoms reported<sup>a</sup>

		MD category (n)					
Symptom	Patient response	Early	y Moderate	Advanced	Severe	End stage	P
Difficulty seeing objects to both sides	Yes	12	8	7	5	4	< 0.001
	No	35	18	7	2	1	
Difficulty seeing objects to left side	Yes	7	8	3	4	5	< 0.001
	No	40	18	11	3	0	
Difficulty seeing objects to right side	Yes	4	7	6	3	4	< 0.001
	No	43	19	8	4	1	
Trouble differentiating colors	Yes	5	4	3	2	4	0.001
	No	42	22	11	5	1	
Trouble differentiating boundaries	Yes	5	2	2	2	3	0.01
_	No	42	24	12	5	2	
As if looking through dirty glasses	Yes	8	5	7	2	3	0.01
	No	39	21	7	5	2	

<sup>&</sup>lt;sup>a</sup> Only symptoms with a statistically significant association (P < 0.05) are shown.

TABLE 5. Areas of VF defects by better eye and worse eye

Areas of VF defect	Better eye (n)	Worse eye (n)
Normal	18	3
Nonspecific pattern of depressed points	17	13
Mild generalized field depression	12	9
Nasal step	11	10
Paracentral scotoma	4	7
Superior arcuate defect	18	11
Inferior arcuate defect	2	5
Both arcuate defect and nasal step	6	7
Both superior and inferior arcuate defect	2	11
Constricted VF	5	17
Severe generalized field depression	2	6
Total	97	99

at the "periphery" may also play a role in difficulty seeing to 1 or both sides, as shown in Figure 3. This is supported by Tochel et al<sup>29</sup> who reported that patients with glaucoma have abnormally high-contrast thresholds (ie, low-contrast sensitivity) without correlation to field loss. It was not possible to determine agreement between laterality of field loss and laterality of symptoms reported for 24 eyes in our study. These patients had a nonspecific pattern of field loss or paracentral scotoma that was neither predominately right sided or left sided.

With increasing amounts of field loss, the likelihood of having visual symptoms increased, as would be expected. For each of the 6 symptoms that showed an association with higher MD score, patients with field loss worse than MD +9.4 dB were more likely to report symptoms. This suggests that patients can have significant field loss before reporting visual symptoms. A previous study speculated that patients with glaucomatous

field defects may experience cortical reorganization or a filling in phenomenon.<sup>30</sup> The defect may be concealed by the colors and patterns of the surroundings such that the brain composes a plausible image.<sup>30</sup> In the study by Crabb et al<sup>28</sup>, 16% of patients selected the image with missing patches in their vision, which was designed to illustrate the filling in phenomenon. Similarly, our study found that 26% of patients reported areas darker or missing in their vision. These findings suggest that what patients actually see is more complex than VF alone, and that patients with glaucoma do not simply develop "tunnel vision."

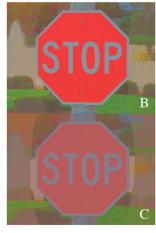
Most patients in our study had good visual acuity, but 92% of patients reported at least 1 visual symptom. Patients may have poor image quality even in those with good visual acuity. All patients who did not report any visual symptoms had VF defects in their better eye, indicating the asymptomatic nature of early disease even in the presence of objective VF defects.

Teaching people that glaucoma causes loss of peripheral vision may teach them to ignore the early signs of glaucoma. We found that the most common symptoms reported by patients with early or moderate glaucoma were needing more light, blurry vision and seeing glare. Even mild or moderate glaucomatous vision loss is associated with significant visual disability and reduced ability to perform visually related tasks, such as reading or driving. <sup>17,31,32</sup> Furthermore, there is reduced quality of life and increased depression rates among patients with increasingly severe glaucoma. <sup>33,34</sup> Earlier detection of disease and implementation of treatment may help preserve visual function and improve quality of life. Providing insight about visual symptoms due to glaucoma may be helpful for clinicians, patients and researchers. We therefore recommend that these symptoms be emphasized to patients at risk for glaucoma in public awareness campaigns and in educational materials.

An important limitation of this study was the inability to determine the actual cause for the visual symptoms described. Since other known causes for decreased vision were excluded, most had excellent visual acuity, and none had a visually symptomatic cataract, the presumption is that the cause for the symptoms was glaucoma.

FIGURE 3. A graphic illustration of a possible progression of visual loss in a patient with glaucoma. (A) Normal vision, early glaucoma. (B) Early loss of contrast sensitivity. (C) Severe loss of contrast sensitivity. (D) Light paracentral and arcuate scotomas. (E) Dense scotomas. (F)

Advanced bilateral disease. (G) Very advanced bilateral disease.







There are several other limitations. The nature of symptoms reported suggests that loss of contrast sensitivity plays role in glaucoma, but we cannot directly verify loss of contrast sensitivity in our patients because it was not measured. Symptoms reported may have been due to loss of contrast sensitivity, acuity or field, and their relative impacts are not clear. We did not test for near visual acuity, which may also have contributed to some of the symptoms reported, such as blurry vision.

Although we assessed visual symptoms by asking how patients see, we did not determine which eye was responsible for the symptoms reported. It has been shown that functional ability and quality of life is closely related to vision status in the better eye, <sup>35–37</sup> so we analyzed patient responses using the better eye MD. Previous studies have found that monocular VFs overestimate vision loss compared with binocular integrated VFs. <sup>38,39</sup> This is a limitation of our study, and our future studies will consider including both monocular and integrated VF assessments. Also, after stratification of our patients by MD category, race differed between the 5 groups, which may have confounded our results.

Despite these limitations, this is a novel study investigating visual symptoms reported by patients with glaucoma. We asked patients specific detailed questions about how they see to gain a better understanding of vision loss caused by glaucoma. Our study found that the most common symptoms reported by all patients, including those with early or moderate glaucoma, were needing more light and blurry vision. Vision loss in patients with glaucoma is not as simple as the traditional view of loss of peripheral vision or "tunnel vision."

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## **APPENDIX**

"What do patients with glaucoma see?" study questionnaire		
1) Do you wear glasses?	YES	NO
2) Is your vision normal?	YES	NO
3) (If you wear glasses, then with them) do you see as well as you did 5 years ago?	YES	NO
If "NO," go to question 4		
If "YES," go to question 5		
4) How is your vision different?		
5) (If you wear glasses, then with them) do you see as well as you did 15 years ago?	YES	NO
If "NO," go to question 6		
If "YES," go to question 7		
6) How is your vision different?		
7) (If you wear glasses and you feel your vision is worse now versus 5/15 years ago), Is your vision worse because you need your glasses more?	YES	NO
8) When you wear your glasses, do you see as well as you did 15 years ago?	YES	NO
9) Is your vision "blurred"?	YES	NO
10) Is your vision "grainy"?	YES	NO
11) When light shines directly on your eyes, do you see a glare?	YES	NO
12) When you look at a picture, do you have trouble differentiating the boundaries?	YES	NO
13) Does it seem as if the world is darker?	YES	NO
14) Do you have difficulty seeing objects off to both sides?	YES	NO
15) Does it seem as if you are looking through a veil?	YES	NO
16) Do you need more light?	YES	NO
17) Do you have difficulty seeing objects off to the left side?	YES	NO
18) Does it seem as if you are looking through clouds?	YES	NO
19) Is there too much light?	YES	NO
20) Are there areas you do not see?	YES	NO
21) Does it seem as if you are looking through dirty glasses?	YES	NO
22) Do you have problems with colors?	YES	NO
23) Do you have difficulty seeing objects off to the right side?	YES	NO
24) When you are reading, do the letters seem faded?	YES	NO
25) (If participant has mentioned a difference in the right vs. left eye) Have you tried seeing with only 1 eye at a time by covering 1 eye and looking with the other?	YES	NO
If "YES," go to question 26		
If "NO," go to question 27		
26) What do you see when you do that?		
27) Is there an area or are there areas which seems darker or even missing?	YES	NO
If "YES," where are the missing areas? (check all that apply)		
Off to the left side		
Off to the right side		
Off to both sides		
Straight ahead		
Up above		
Down below		
Somewhere else		